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ABSTRACT

The document describes a project to initiate effective services for hearing impaired developmentally disabled (HIDD) individuals, thereby contributing to their deinstitutionalization. An introductory chapter presents the background for establishment of the regional demonstration center at the University of Arizona. Chapter 2 addresses general and specific project objectives, problem areas, hypothesis and expected results or benefits, methodology, and projected functions. Chapter 3 focuses on administrative aspects of the project. A fourth chapter presents a description of the initial service, research, and training activities of the project. Also discussed are the apparent reasons why so little has actually occurred in the past regarding the establishment of special services. A fifth chapter offers descriptive population information on HIDD persons, while a sixth chapter gives an overview of the project's service activities (which include casefinding and referral, audiological screening and assessment, counseling, parent education, sheltered residential living/training, and prevention). Chapter 7 reviews several models that can be used in reorganizing services for HIDD children and adults. A model for the analysis of school and agency services is detailed in an eighth chapter, followed by a chapter which reports problems in the area of personnel preparation at the degree level. Chapter 10 describes the need for short term inservice training, what the project has accomplished in this area, and the models for short term training the project has developed. Publications and related dissemination activities of the model demonstration program are listed in Chapter 11. Chapter 12 offers information and sample letters relating to assessment of the program. Future recommendations for services, research, and training are outlined in a final chapter. Among appendixes are sample forms, an independent living skills inventory, an outline for a graduate level introductory course on hearing impairment and the developmental disabilities, and a report by J. Perine titled "A Model for Community-Based Residential Programing for HIDD Persons." (SBH)

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
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Hearing Impaired Developmentally Disabled Persons

A Challenge to the Helping Professions

by
Larry G. Stewart, Ed.D.

FINAL REPORT

Model Demonstration Program
HEW Grant No. 4-P-7114419
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DEDICATION

This publication is dedicated to the hearing impaired developmentally disabled children and adults who taught us what we were doing wrong, that future generations might benefit from what is right.

ACKNOWLEDGEMENTS

The Model Demonstration Program for Hearing Impaired Developmentally Disabled Persons was made possible through the combined efforts of many, many dedicated persons. These persons gave freely and willingly of their time, knowledge, and resources in planning the project, in helping the staff to operate it, and in providing support in times of need – which were frequent. It is fitting that this help be acknowledged at the beginning of this final project report.

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University Executive Council: Dr. George Leshin (Chairman for three years), Dr. Willis Brewer, Dr. Samuel Kirk, Dr. Karen Newman, Dr. Amos Sales (1977-79), Richard Saltford (1976-78), Dr. Paul Skinner, Dr. David Wayne Smith, Dr. Marsden Stokes (1976-77), and Dr. Armin Turechek.

National Advisory Committee: Dr. S. Richard Silverman (Chairman), Max Addison, Wallace K. Babington, Dr. William Healey, Dr. Lee Henney, Dr. Sam Kirk, U.S. Senator Dennis DeConcini, Dr. Robert Lennan, Tadashi Mayeda, Dr. Roberto Rendon, and Dr. Frederick Schreiber.

Deep appreciation is expressed here to these individuals, whose assistance was of crucial importance throughout the project.

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The staff of the project deserves mention here in appreciation for their individual contributions. The staff consisted of the following persons:

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Selected portions of this final report were prepared by Vicki Palm (see the suggested graduate curriculum for teacher preparation in Appendix D), Joseph Perine (see the model for residential living in Appendix D) and Mike Milone (see the chapter on HIDD population, specifically the section dealing with project clientele data). Their assistance is appreciated and acknowledged here.

The COPD Group Home/Independent Living Curriculum materials were prepared by COPD staff, led by Roger Beach and, later, Marguerite Harmon (see Appendix D). Their assistance is appreciated.

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The assistance of two unusual individuals was of special value to me in my role as project director from the beginning of the project in October, 1976, until its completion with this final report. Dr. David Wayne Smith, Office of the Vice President, University of Arizona Health Sciences Center, believed in the project and gave it his total support at a time when there was serious question regarding its feasibility as a component of the University of Arizona. Dr. Smith's support, and this support alone, was the reason for the decision of the University to sponsor the project. In his actions, Dr. Smith evidenced one of the qualities that make him

stand tall among professionals who work with the handicapped – the vision that melds services in new, unexplored areas of serving the handicapped with the traditional functions of a university – research and training. The results of this project will, it is hoped, validate the soundness of the "new services"/research/training concept within a university setting as so vigorously supported by Dr. Smith.

Ms. Debi Richardson, my administrative assistant from the inception of the project until her departure for a new position in late 1978, enhanced the development and operation of the project through her excellent office organizational and management skills. Her fine work, and her unwavering loyalty to the goals of the project under conditions of great challenge, are gratefully acknowledged here.

Finally, deep appreciation is extended to the hearing impaired developmentally disabled children and adults who assisted the project by teaching us their problems and needs. This book is dedicated to them.

Larry G. Stewart, Ed.D.
Project Director
October, 1976 - September, 1979

TABLE OF CONTENTS

Page

Dedication

Acknowledgements i

Table of Contents v

Chapter 1 – Introduction to the Background of the Model Demonstration Program. 1

Chapter 2 – A Review of the Proposed Model Demonstration Program for Hearing Impaired Developmentally Disabled Persons 7

Chapter 3 – Establishment and Operation of the Model Demonstration Program: Administrative Aspects. . . . 31

Chapter 4 – Services for HIDD Persons: Implementing Initial Strategies and Rationales 43

Chapter 5 – Hearing Impaired Developmentally Disabled Persons: Description Population Information 67

Chapter 6 – Services Provided by the Model Demonstration Program. 103

Chapter 7 – Service Models for Children and Adults with Hearing Impairment and Developmental Disabilities. . 123

Chapter 8 – Analyzing Services for the Hearing Impaired Developmentally Disabled. 141

Chapter 9 – Models for Graduate Education in the HIDD Area 149

Chapter 10 – Short Term Training in the HIDD Area: Needs, Accomplishment, Models 155

Chapter 11 – Publications and Related Dissemination Activities of the Model Demonstration Program 165

Chapter 12 – Assessment of the Model Demonstration Program. 169

Chapter 13 – Recommendations for the Future. 191

Appendix I – Model Demonstration Program Hearing Impaired Developmentally Disabled Persons 197

Appendix II – VIF and Associated Correspondence 205

Appendix III – Community Outreach Program for the Deaf Group Home 215

Appendix IV – A Model for a Graduate Level Introductory Course on Hearing Impairment and the Development Disabilities. 235

Appendix V – A Model for Community-Based Residential Programming for HIDD Person. 245

CHAPTER 1

INTRODUCTION TO THE BACKGROUND OF THE MODEL DEMONSTRATION PROGRAM

The Moded Demonstration Program for Hearing Impaired Developmentally Disabled Persons was established in October, 1976, by the Rehabilitation Center, College of Education, The University of Arizona, Tucson. Funds for the project were provided by the Developmental Disabilities Office (now the Bureau of Developmental Disabilities), Office of Human Development, U.S. Department of Health, Education and Welfare. These Federal funds, totaling 1.25 million dollars over the course of the three years of the project, were made available under Public Law 94-103, otherwise known as the Developmental Disabilities Assistance and Bill of Rights Act of 1975.

The Developmental Disabilities Office (D.D.O.), in funding the Model Demonstration Program, designated it as a project of national significance in recognition of the national scope of the problem to be addressed by the three year project. Significantly, the first year of the project was funded for $500,000, the largest single grant provided by D.D.O. in its "projects of national significance" category for the 1977 Fiscal Year. This funding level suggests the relatively crucial nature of the project.

The Model Demonstration Program was established in response to a pressing, longstanding need throughout the country for more and better *organized* education, habilitation, and rehabilitation programs for hearing impaired persons who *also* are further handicapped by one or more of the disabilities classified by Public Laws 94-103 as "the developmental disabilities". Referring to P.L. 94-103 (89 stat. 486, 1975), the developmental disabilities are defined in this manner:

(7) The, term 'developmental disability means a disability of a person which–

(A) (i) is attributable to mental retardation, cerebral palsy, epilepsy, or autism;
(ii) is attributable to any other condition of a person found to be closely related to mental retardation because such condition results in impairment of general intellectual functioning or adaptive behavior to that of mentally retarded persons or requires treatment and services similiar to those required of such persons; or
(iii) is attributable to dyslexia resulting from a disability described in clause (i) or (ii) of this subparagraph;

(B) originates before such person attains age eighteen;
(C) has continued or can be expected to continue indefinitely; and
(D) constitutes a substantial handicap to such person's ability to function normally in society.

The history of education and other human services in the United Stated reveals that over the years handicapped persons have been served by programs that were both designed and oriented *primarily* toward serving persons with a single specific disability. There have been, and are, for example, separate and distinct schools, organizations, and agencies that offer specialized services and assistance to the deaf, to the blind, to the mentally retarded, to epileptic persons, to persons with cerebral palsy, to autistic persons, to the mentally ill, and to persons with behavior disorders.

Seldom have there been, or are there now, services that are designed, staffed, and operated in accordance with the identified needs of persons who have *combinations* of major disabilities. To be sure, there are some such programs, and especially so since the advent of P.L. 94-103 (The Disabled Assistance and Bill of Rights Act of 1975), P.L. 94-142 (The Education for All Handicapped Children Act of 1975, 89 Stat. 733-1975), and P.L. 93-112 (The Rehabilitation Act of 1973, 87 Stat. 355-1973) which mandate individualized services. However, a close look at extant programs in schools, agencies, and other organizations will verify that even today the great majority of programs continue to emphasize services oriented toward a single disability category.

What this program focus upon one major disability often meant was either underservice or actual neglect of other major disabilities.

Schools for deaf children have traditionally organized their program of services around the educational and communication needs generated by moderate to profound deafness. Little attention has been given by these schools to the special needs of deaf persons who are also emotionally disturbed, developmentally disabled, or otherwise multiply disabled.

Schools and programs for the developmentally disabled, for the emotionally disturbed, for the blind, and for other disabled persons have organized their services based upon the educational and developmental needs of these single specific disabilities. These schools and programs have generally overlooked the needs generated by other major disabilities, and especially so with the communication and language needs of deaf children and adults since these are so complex and little-understood by non-specialists.

Such a single-category disability program emphasis is understandable,to an extent, when we consider the complexities involved in providing quality services to children and adults who are disabled by such single major disabilities as deafness, blindness, the developmental disabilities, and mental illness. Understanding a disability such as deafness, learning of its profound impact on development and

learning, and acquiring skills in teaching or counseling the deaf requires graduate study usually covering two years or more. The same may be said of learning to teach or counsel the mentally retarded, the mentally ill, the blind, and so on. Hence, to prepare personnel to serve individuals having two or more disabilities appears to be a very difficult goal to achieve given the current lack of incentives to do so (i.e., no special salary increases, no special recognition, difficult and often frustrating professional tasks, inadequate instructional materials).

Yet, despite the reality of the problems that have led to the single disability program emphasis, there are *multiply* disabled children and adults who require specialized services to help them with *all* of their special needs. Unfortunately, such comprehensive special help has usually not been *available.* As described above, multiply disabled children and adults historically have received primarily only those services emphasized by the school or program where they have been placed. The deaf mentally retarded child in the school for the deaf, for instance, is given services that respond to his deafness whereas this same child, if placed in a program for the mentally retarded, is provided with services that respond to mental retardation. The same story is seen repeated with the deaf child who is autistic, the deaf child who has cerebral palsy, and the deaf child who has epilepsy. Even more unfortunate, perhaps, is the deaf person with two or more of the developmental disabilities who received services for only one of these disabilities.

In 1975, in a report prepared by the Steering Committee on "The Rehabilitation and Management of the Hearing Impaired Mentally Retarded" (Healey, 1975) the following statement appeared:

> Severe hearing impairment in combination with mental retardation presents unique and complex problems for society and its citizens. The burden placed on families of persons with a dual handicap can be devastating and immeasurable. Lack of comprehensive, quality services has often resulted in educational, vocational and social disabilities of catastrophic proportions for the severely hearing impaired mentally retarded population.

The following statement was made in still another publication:

> Currently, *nine* of every *ten* such persons are confined to public institutions for the mentally retarded. Few receive services through community integrated programs or in residential schools for the deaf. (*Task Force Report on the Mentally Retarded Deaf*, 1973)

In *The Hearing Impaired Mentally Retarded: A Survey of State Institutions for the Retarded,* Brannan, Sigelman and Bensberg (1975) reported in their review of the literature,

> . . . very little [was] known about current programming for the Hearing Impaired/Mentally Retarded person. . .

> According to most observers, the HI/MR resident has traditionally received no training to speak of, or has had access to general training and education programs within the institution, but has not often participated in programs specifically designed for the HI/MR student. (Page 27)

Reporting on their findings, the authors go on the state:

> When a disability is perceived as serious and widespread, we expect to witness the development of special programs designed to meet special needs. Facilities were asked this very important question: Does your facility have a distinct program for the (1) hard of hearing, (2) deaf, or (3) deaf and hard of hearing in a combined setting? Of the 158 institutions surveyed, only 76 (48%) checked one or more options. In other words, slightly over half of the institutions did not have a distinct program for any hearing impaired group. Of the 76 which clearly felt that they had one or more distinct programs, the majority (59%) had a single program serving both the deaf and hard of hearing. Another 16% had a distinct program for the deaf and a distinct program for the hard of hearing, while 9% had a distinct program for the deaf only. A few facilities (12% of the 76) checked all three options, apparently indicating that they had distinct programs for the deaf, hard of hearing and deaf and hard of hearing combined. A few facilities spontaneously mentioned that they operated specially-funded Deaf-Blind programs. . . . we can conclude that most public institutions do not perceive themselves as offering distinct programs for the hearing impaired. Those who do provide distinct programs generally work with the deaf and hard of hearing as a single, hearing impaired group (Brannan, *et. al.*, 1975, Pp. 27-28)

This status of underdevelopment of services for HI/MR persons is reflected in schools for the deaf and classes for the deaf within public schools. There, programming is based more upon student classification as "multiply handicapped" than according to specific needs, and relatively few schools and classes report having significant numbers of hearing impaired developmentally disabled students (Healey, 1975; *American Annals of the Deaf*, April, 1979).

In attempting to achieve greater understanding of the causes for the lack of development of appropriate services for HI/MR individuals, the previously cited Steering Committee for the project on "Rehabilitation and Management of the HI/MR" reported:

> Despite a general increase in funding for the handicapped by both government and the private sector, no state has implemented comprehensive services that fulfill the full range of needs of the HIMR population.
>
> State officials contacted during this project cited inadequacy of funds and insufficient resources as the major problems. A closer study

of the problems, however, reveals much more. Categorically, the problems include:

- Lack of information
- Lack of coordinated planning, management, and program evaluation (especially among state and local agencies of health, education, and welfare)
- Lack of sufficient resources

(Healey, 1975, p. 19)

These problems and others have plagued the development of services not only for HI/MR individuals but also for those hearing impaired persons having other developmental disabilities. With the increasing concern over this lack of services for HIDD persons as generated by various governmental task forces and steering committees, a major response was inevitable. This response came, finally, in 1976, when the U.S. Department of Health, Education and Welfare issued a request for proposals (RFP) for the establishment of a regional demonstration center for hearing impaired developmentally disabled persons.

The HEW request for proposal guidelines stated, in part:

> This dual-handicapped population requires national attention. Historically, many of these persons either have been denied services, or too often, have been inappropriately placed in traditional programs for the deaf or the mentally retarded that are unequipped to cope with their instructional and other service needs. Weinstraub *et. al.'s*, data (1971) indicated that nearly 900,000 children classified as hearing impaired, mentally retarded and multiply handicapped were not receiving special services or instruction. (HEW RFP HIDD Guidelines, 1976)

The guidelines cited above, in focusing upon the basic mission that was conceptualized for a regional demonstration center, stated:

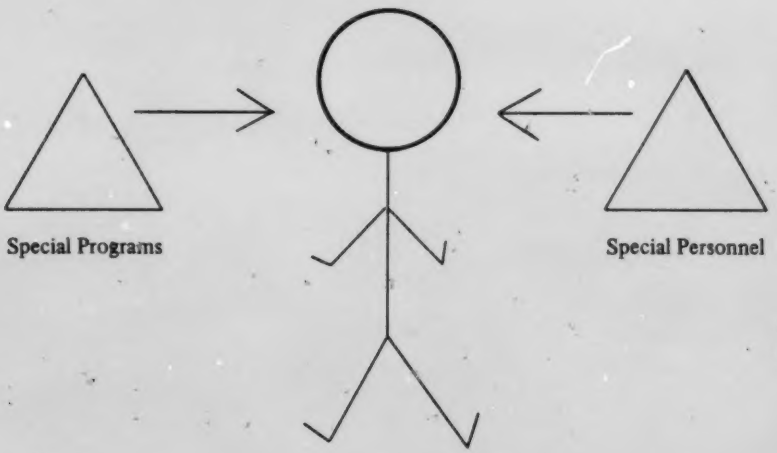
> The Office for Handicapped Individuals and the Office of Developmental Disabilities, in an initial step toward meeting the national obligation to serve the HIMR, intend to commit a limited amount of Federal resources to create a Regional Demonstration Center for HIMR populations which will cooperate with existing regional centers for the handicapped, university-affiliated facilities willing to develop a special interdisciplinary training curriculum and practicum, and service programs for the hearing impaired and the mentally retarded.
>
> This demonstration center should serve approximately 20 to 30 HIMR persons at one time and carefully design programs to serve persons with all degrees of disability as well as variances in age range . . . Such a demonstration center should evaluate and disseminate information on new and improved methods for teaching and managing the HIMR population. (HEW RFP HIDD Guidelines, 1976)

We see, in these guidelines, emphasis upon the hearing impaired mentally retarded population. However, as it turned out this first regional demonstration center was subsequently charged with the challenge of implementing new services for not only mentally retarded persons with hearing impairment but also for hearing impaired persons with the other developmental disabilities – autism, cerebral palsy, and epilepsy.

This chapter has presented the background for the establishment of the nation's first regional demonstration center for hearing impaired developmentally disabled persons, located at the University of Arizona.

From October, 1976, until the end of September, 1979, the Model Demonstration Program operated as an intensive special project designed to develop service, research, and training strategies, content, and processes having the end goal of advancing the state of the art in serving HIDD children and adults. The chapters that follow describe the project, its operations and activities, and, finally, its achievements and recommendations for the future.

The Model Demonstration Program "story" is an unusual one. It is a story with a special message for advocates and for the professionals who serve HIDD individuals and their parents. This story is not for the reader who is convinced that special populations such as HIDD persons can be adequately served by generic programs with general (as opposed to specialized) personnel. Rather, it is for those who believe that special programs and special workers are essential for helping special people. This knowledge, and its application, is the challenge to the helping professions of tomorrow.



CHAPTER 2

A REVIEW OF THE PROPOSED MODEL DEMONSTRATION PROGRAM FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS

In August, 1976, the Department of Health, Education and Welfare announced its request for proposals for the first (and, at this writing August, 1979, the only) Regional Demonstration Center for the Hearing Impaired Developmentally Disabled. Responding to this RFP, the University of Arizona submitted what was to become the proposal eventually selected by HEW for carrying out the three-year project. The proposal, in somewhat condensed form, is described in this chapter. Tenses have been changed to reflect the proposal's place in time (1976).

General Objective

The general objective of this project by the University of Arizona was to design and implement activities impacting, in a substantial manner, upon the state of the art in serving multiply handicapped hearing impaired mentally retarded persons of all ages from infancy through adulthood. Means were to be developed and documented for initiation of effective services for hearing impaired mentally retarded (HIMR) individuals, thereby contributing to their deinstitutionalization. These new service means were to be disseminated on a regional and national basis, thereby permitting the project to set in motion a multiplier effect nationally on behalf of HIMR persons.

Specific Objectives.

The specific objectives of this proposal for a Model Demonstration Program for HIMR persons were:

(1) To establish and operate a model demonstration program designed to serve as an experimental, research, training, and development facility in the development of specific techniques for optimizing the growth and development of HIMR persons;

(2) To develop, and facilitate the operation of, a well-coordinated chain of services impacting on the well-being and development of HIMR persons. Within this chain of services the applicant agency will serve a coordinating function which will create a synergistic effect for the benefit of HIMR individuals;

(3) To develop innovative methods, materials, curricula, and personnel expertise resulting in effective diagnostic, educational, and service programs for HIMR person;

(4) To document specific innovative training and service techniques for HIMR individuals as applied and tested for effectiveness within the Model Demonstration Program and cooperating agencies;

(5) To develop an operational administrative model that effectively coordinates a broad range of interdisciplinary services for HIMR persons of all ages;

(6) To disseminate information regarding project-developed innovative methods, materials, curricula, and personnel training techniques that have been demonstrated to result in effective diagnosis, education, and services for HIMR individuals from infancy through adulthood.

Problem Areas

A recently completed project entitled "Rehabilitation and Management of Hearing Impaired Mentally Retarded" and sponsored by the Department of Health, Education and Welfare clearly identified the major problems that continued to hamper efforts to improve services for HIMR persons. These major problems centered around lack of information, lack of coordinated planning, management, and program evaluation, and lack of sufficient resources (Healey, 1975, p. 19).

1. *Lack of Information.* As almost all other states in 1975, Arizona had insufficient information regarding the hearing impaired mentally retarded. This lies at the heart of such difficulties as defining the population, communicating this definition to other agencies, identifying the population in a regular fashion, developing an effective manpower pool, and implementing a quality service and program evaluation system. Arizona had agencies that had been specifically assigned responsibility for serving mentally retarded persons, but the focus thereby generated had not been sharp enough to differentiate between the needs of the mentally retarded and the hearing impaired mentally retarded. Even when efforts to zero in on the HIMR had been made, they encompassed the "multiply handicapped hearing impaired," a still-loose classification which includes the deaf-blind, deaf-emotionally disturbed, and deaf-mentally retarded, among others. Further, agencies and personnel had been unable to adequately develop suitable diagnostic and education/training curricula and materials for the population, primarily due to fragmentation of efforts and lack of program focus. These problems stemmed from a severe manpower shortage.

2. *Lack of Coordinated Planning, Management, and Evaluation.* In Arizona as elsewhere, there was no coordinated system of services for the hearing impaired mentally retarded. Lacking such a system, inadequate management and program evaluation are logical outcomes. Comprehensive statewide planning for the hearing

impaired mentally retarded had not yet occurred in the state, although a beginning had been made in some other states. Better coordinated efforts were needed to prevent hearing loss, develop interagency referral systems, implement interagency data systems, coordinate state-operated programs for the HIMR, and develop a center or centers where parents, professionals, and others could come for information and assistance (Healey, 1975, p. 20). For HIMR persons, Arizona had the Arizona Training Program, a statewide system of centers for the mentally retarded, and Arizona Diagnostic, Treatment and Education Center (under the Arizona State School for the Deaf and the Blind), along with several support system agencies such as public schools, Vocational Rehabilitation, and Welfare Services. However, interagency linkages were relatively weak at that time, services were essentially uncoordinated, and specific focus upon the HIMR had been weakened by the simultaneous attention to other multiply handicapped children ("sensory impaired," "multiply handicapped," etc.). While federal and state funding was available for providing more focused services, the lack of professional attention to HIMR persons had resulted in failure to bring these funds to bear upon this population. Project planners thought that a well-coordinated system would ensure access to state and federal funds and appropriate systematic program development.

3. *Lack of Sufficient Resources.* As pointed out, in 1976, Arizona had several state-supported agencies providing services to the hearing impaired mentally retarded. However, the agencies involved also had other areas of responsibility. As a result, manpower development, curricula preparation, diagnostic efforts, and education/training service for meeting the needs of HIMR persons were not priorities. There was no university in the state or region providing preparation for teachers and others who desired to serve the mentally retarded hearing impaired, and as a consequence service programs were limited in their ability to recruit individuals having expertise with the HIMR. Diagnosis, while often of good quality once an individual entered certain existing centers, too often failed to reach those individuals in rural areas, infants and some individuals institutionalized for years under an improper diagnosis. Too, many HIMR youths were improperly placed within the regular public school for lack of proper diagnosis.

The fact that Arizona and the region had large numbers of Spanish speaking and Indian peoples, with their own customs, presented special problems.

Even when a child had been diagnosed as hearing impaired mentally retarded, his/her needs too often went unmet because of a lack of well-articulated curricula and materials for instructional purposes. Under these circumstances, it was easy to understand why Arizona and most of the nation lacked facilities designed for the hearing impaired mentally retarded.

4. *Need for this Assistance.* The national need for improvement in services for HIMR persons was set forth above. In Arizona and in the surrounding area in 1976 this need was readily apparent to knowledgeable professionals. However, as Arizona attempted to organize and implement efforts to meet the needs of HIMR persons in the region and to serve as a multiplier catalyst, support from the Developmental Disabilities Office was requested based upon the following rationale.

Arizona had several basically strong facilities and programs serving the deaf, the mentally retarded, and the multiply handicapped mentally retarded. These programs included the Arizona Training Program (with large facilities in Coolidge, Phoenix, and Tucson), the Arizona Diagnostic, Treatment, and Education Center in Tucson, the Arizona State School for the Deaf and the Blind, the State Department of Education, the Rehabilitation Services Bureau, Services for the Blind and Visually Impaired, the Southwest Deaf-Blind Center program in California. The University of Arizona College of Education, through its Special Education Department, offered teacher training in the area of deafness and, separately, in the area of mental retardation. The College's Rehabilitation Center offered training in the area of Rehabilitation Counseling with the Deaf as well as in Vocational Evaluation. The College of Medicine and its Medical Center offered training in the health and allied health professions. The State of Arizona had an effective Developmental Disabilities Advisory Council and a State Department of Mental Retardation, both functioning within an umbrella agency (Arizona Department of Economic Security). The Department of Economic Security had a state advisory council on communicative handicaps, which had demonstrated special interest in the needs of the hearing impaired. Numerous allied agencies offered services in such areas as audiology, speech and hearing, medicine, casefinding and referral, parent assistance, health and welfare, vocational training, and habilitative/rehabilitative services.

We see, then, a broad and impressive array of comprehensive services in Arizona that had the potential for impacting most substantially upon the state of the art in serving hearing impaired mentally retarded persons. Contacts had been made with all of these organizations and agencies regarding this proposal, and all were enthusiastic about participating and becoming a link in a coordinated chain of services for the HIMR. However, administrative expertise, planning, professional training efforts, curricula and materials development, community resources development, and program evaluation efforts were required in order to create a coordinated system. Support from the Developmental Disabilities Office would permit Arizona to mount these efforts.

5. *Planning Studies Data.* Interested parties within Arizona had followed developments concerning hearing impaired mentally retarded persons for several years with increased attention in 1975 as a result of the establishment of the Arizona Diagnostic, Treatment, and Education Center in that year and the publication of the *Hearing Impaired Mentally Retarded* (Healey, 1975). In April, 1976, a group of interested persons representing several of the prospective cooperating agencies in this proposal met to discuss the needs of hearing impaired mentally retarded persons. This meeting, held at the University of Arizona Medical Center, resulted in the decision to contact agency heads and ascertain their opinions regarding the priority of serving HIMR persons. The decision was also made to develop a "parameters" description of the activities that might be attempted in Arizona. Subsequent meetings of the group were held on May 6, and August 17, 1976. These meetings reaffirmed the consensus that improving services for the HIMR population should be a top priority effort for the State, and developed a

sharper outline regarding how this improvement might take place. Special attention was given to funding resources, and when the request for Proposal on this project arrived from the Developmental Disabilities Office, HEW, the agreement was reached to prepare a proposal for a Model Demonstration Program for Hearing Impaired Mentally Retarded Persons. (Note: Ag[illegible], we see the HIMR focus at the time, rather than HIDD).

Agencies and organizations represented in early planning efforts included:

Arizona Developmental Disabilities Planning and Advocacy Council (ADDPAC)
Arizona Diagnostic, Treatment, and Education Center (ADTEC)
Arizona State School for the Deaf and the Blind (ASDB)
Arizona Training Program (Coolidge, Phoenix, Tucson)
Bureau of Child Development, Children's Hospital, Tempe
College of Education (Departments of Rehabilitation and Special Education), University of Arizona
College of Medicine (Departments of Nursing, Family and Community Medicine, Health Sciences), University of Arizona
Community Outreach Program for the Deaf (COPD)
Division of Special Education, State Department of Education
Indian Health Services
Maternal and Child Health, State of Arizona

These groups were unanimous in supporting this proposal.

In the planning of this proposal, questions were raised regarding definitions of the population and the region to be served. These questions were addressed as follows:

(1) *Definition of the Population.* The definitions proposed in Healey (1975) were accepted for the purposes of this project proposal.

These were:

a. *Hearing Impairment.* "Hearing impairment is a generic term indicating any loss of hearing from mild to profound as indicated otologically, audiometrically, and functionally. The term generally includes the subclassifications of deaf and hard of hearing." Healey, 1975 p.6)
b. *Mental Retardation.* As expressed by the American Association on Mental Deficiency, mental retardation is ". . . significantly sub-average general intellectual functioning, existing concurrently with deficits in adaptive behavior, and manifested during the development period." (From Healey, 1975, p.8).
c. *The Hearing Impaired Mentally Retarded (HIMR).* The hearing impaired mentally retarded are "those individuals who have hearing impairment, subaverage general intellectual functioning

and deficits in adaptive behavior. The combination of these three factors requires services beyond those traditionally needed by persons with either mental retardation or hearing impairment alone." (Healey, 1975, p. 9).

Size of Population. The publication, *The Hearing Impaired Mentally Retarded* (Healey, 1975), noted that there were no definitive data concerning the numbers of hearing impaired mentally retarded persons in the U.S. However the suggestion was made, based on prevalence studies, that there may have been as many as 1,300,000 children who were mildly to profoundly retarded, with perhaps 10% of them hearing impaired mentally retarded.

In Arizona and the adjacent region there had been no studies documenting the population of hearing impaired mentally retarded persons residing therein. In planning this project proposal, however, the following information became apparent.

Schein and Delk (1974) in a national census of the deaf population (NCDA) reported that one out of every three deaf persons has at least one other disability in addition to deafness. Among deaf respondents 1 to 64 years of age, 1.6% reported also having mental retardation. However, the authors are quick to point out that:

> The NCDP's target population was the civilian non-institutionalized population. Residents of mental hospitals, prisons, institutions for mentally retarded persons, etc., were not included. Since there is some evidence indicative of a disproportionate number of prevocationally deaf persons in institutions . . . the likelihood is that the prevalence rate for deafness in the institutionalized population would exceed that for the noninstitutionalized population. (Schein & Delk, 1974, p. 33)

Brannan, Sigelman, and Bensberg (1975) reported that hearing impaired mentally retarded people do not differ markedly from the general mentally retarded institutionalized population in AAMD classification. This finding tends to reinforce Vernon's (1968) finding that the distribution of intelligence among deaf persons resembles the distribution among the general population. While there have been numerous estimates concerning the number of HIMR persons, the following viewpoint appeared valid:

> Presently, the precise number of persons with severe hearing loss and mental retardations in the United States is unknown and will remain so until additional formal studies and more appropriate services become available . . . data from state education agencies show that approximately 1,300,000 children are mildly to profoundly retarded . . . If a 10% estimate of hearing loss (per Bensberg's data) is applied to this population and combined with the estimates of mentally retarded adults who have significant hearing loss, the

> number of HIMR persons increases drastically to at least 165,000. These estimated data are debatable. However, the need for comprehensive programs and services that include more precise data collection and reporting is uncontestable. (Healey, 1975, p.1)

Authorities seemed agreed that the HIMR population was sizeable and warranted national attention in view of its documented needs.

Consultation with State Developmental Disabilities Office. Project planners contacted the Arizona Developmental Disabilities Planning and Advocacy Council and liaison was continuing as this proposal was completed. The support and assistance of the Council as well as guidance from the Federal Developmental Disabilities Office, was to be sought throughout the conduct of the project if funds were granted to Arizona.

Project Sponsorship. In planning for this proposal, the question of a coordinating agency was a central one. There were several different views on how coordination and project sponsorship might be achieved, but finally the decision was made to have the Rehabilitation Center, College of Education, University of Arizona, Tucson, serve as coordinating agency. The rationale for this decision was: (1) The Rehabilitation Center was in a position to facilitate effective interdisciplinary participation in research and training efforts, a central aspect of the project; (2) The Rehabilitation Center had had broad experience in the area of deafness and also in mental retardation, and had effectively conducted other federal and state projects on their behalf. A three-year facility improvement grant entitled "A Model Community Services Delivery System for the Hearing Impaired" had just recently come to a successful close; and (3) The service program operated by the Rehabilitation Center in support of its professional training programs had working relationships with a broad range of local, state, and national agencies and organizations. These existing ties would be beneficial to the operation of the project. Details of project administration and coordinating functions are presented under the section on Methodology.

HYPOTHESIS AND EXPECTED RESULTS OR BENEFITS

The Model Demonstration Program for Hearing Impaired Developmentally Disabled Persons serving Arizona and a region encompassing the States of Arizona, New Mexico, Nevada, Utah, and West Texas will result in the following benefits:

1. In the area of population identification, there will be developed within the region and maintained by the individual states, state registries of hearing impaired mentally retarded persons from infancy through adulthood. These registries will provide precise information on the number of HIMR person, demographic data, and high risk factors.

2. In the area of screening and initial assessment, procedures will be implemented designed to facilitate referral of all needy hearing impaired mentally retarded persons to services most appropriate for their needs.

3. Community and State agencies capable of providing assistance to hearing impaired mentally retarded persons of all ages will be identified, their services described, and agreement to become a link in a chain of services on behalf of HIMR persons will be obtained. Flow systems between and among these agencies will be developed, described, and shared.

4. Diagnostic procedures, materials, and systems will be developed, implemented, and tested for optimizing the education and training as well as the health of hearing impaired mentally retarded persons.

5. Education, training, habilitative, and rehabilitative curricula, materials, and personnel expertise preparation procedures will be developed, implemented, tested and articulated for dissemination locally, region-wide, and nationally.

6. A system of effective services for the HIMR population will be developed, tested, and described in modular form, making possible its application in whole or in part in other states.

7. The focus of the system of services for the HIMR will be the Model Demonstration Program, augmented by the Arizona Diagnostic, Treatment, and Education Center (ADTEC). This facility will be described in detail in the Methodology section.

METHODOLOGY

Plan of Action. As stated elsewhere, it was thought that providing effective services for hearing impaired mentally retarded persons requires a well-coordinated range of interdisciplinary contributions in the areas of casefinding, parental assistance, diagnosis, education, training, health care, habilitation and rehabilitation. No single agency could meet the diverse needs of HIMR persons from infancy through adulthood (Healey, 1975, p. 19). The plan of action to be undertaken was based upon this fact. The approach to be used was to focus upon the following:

1. *Coordination.* Since coordination of existing services was currently inadequate, a system of coordination was to be developed. This system would originate through leadership from the project staff. The Rehabilitation Center would be selected as project administrator. Core project staff would consist of the following:

a. Project Director–full-time
b. Secretary–full-time

c. Research and Training Coordinator–full-time
d. Instruction Coordinator–full-time
e. Instructional Media Coordinator–full-time
f. Clerk–full-time

Coordination strategies would be developed under the leadership of the project director and central staff. Plans at that time were to meet and reach agreement with the other agencies that would result in the implementation of all phases of the system of services, beginning with agencies involved in family planning and extending through initial casefinding, screening, referral, diagnosis, and other service functions. Project staff were to meet with such agencies to describe the project, ascertain the nature of services that each agency could provide to HIMR persons and their families, reach agreement on referral and case intake procedures, and identify key contact persons. This information was to be used to develop a descriptive brochure for use by all agencies; a companion brochure would be developed for dissemination to parents, allied professionals, and others who might wish to have information about services for the HIMR. In the process of orienting agencies to the project, a flow system was to be developed for the purpose of facilitating optimum placement of HIMR persons. A sample of this flow system is on following page.

Agencies to serve as links in the chain of services for hearing impaired mentally retarded persons included:

Arizona Department of Economic Security

- Services for the Blind and Visually Impaired
- Vocational Rehabilitation
- Food Stamps
- Welfare
- Department of Mental Retardation, including the Arizona Training Programs in Coolidge, Phoenix, and Tucson

Arizona Developmental Disabilities Planning and Advocacy Council
Arizona Diagnostic, Treatment and Education Center
Arizona State School for the Deaf and the Blind
Bureau of Child Development, Children's Hospital
Community Outreach Program for the Deaf
Indian Health Services
Maternal and Child Health
Mental Health Department
Special Education programs in public school systems
Speech and Hearing Clinics

The above-listed were to be initial participants. Project staff were to utilize resource books such as the *Tucson Health Resource Directory* (November, 1975) and publications for Phoenix and the state government to identify other potential participating organizations.

ARIZONA MDP

Sample Flow System for Referral Purposes

1. *Contact made with system agency*

2. Information on HIMR Services given to parents or corollary

3a. If resident of *Southern Arizona*	3b. If resident in *rural area*	3c. If resident of *Central Arizona*
Referral made to Model Center (ADTEC)	Referral made to Field Unit Services	Referral made to satellite Model Center (Arizona Training Program, Coolidge)

4. Initial intake for screening purposes

5. Diagnosis
   a. Medical (local)
   b. Specialized medical
   c. Social
   d. Family
   e. Psychoeducational
   f. Audiological

6. Services
   a. Medical
   b. Family
   c. Transportation
   d. Education
   e. Training
   f. Habilitation
   g. Rehabilitation
   h. Speech and Hearing
   i. Placement
   j. On-going support as needed

The project staff would initially serve to coordinate the development of this services linkage system; by the end of the three-year period the system was to be structured to maintain its linkages under the leadership of select member agencies such as the Department of Economic Security, the Arizona Diagnostic, Treatment, and Education Center, and the Arizona Training Program.

1. *Project Services.* Within the scope of project activities, direct services were to be provided to hearing impaired mentally retarded persons of pre-school age, school age, adolescents, and adults. These services were to include, but not be limited to:

a. Prevention programs
b. Identification
c. Comprehensive interdisciplinary assessment or diagnostic evaluation
d. Referral for additional services
e. Parent or guardian instruction and counseling
f. Student/client counseling and placement
g. Staff guidance and inservice orientation/instruction
h. Direct management (medical, educational/vocational/social Recreational)
i. Individual reassessment and consultation
j. Record and data maintenance

In addition, professional training was to be offered in the area of serving hearing impaired mentally retarded persons. Such training was to be of a short-term nature, through workshops and conferences, or long-term leading to an advanced professional degree in such areas as nursing, psychology, rehabilitation, and special education. Research and program evaluation, along with curriculum and materials development, were to be major areas of focus. Technical consultation with personnel in the region and throughout the nation would be provided.

3. *Program Types and Alternatives.* The following program types and alternatives would be provided: diagnostic center placement; special class educational placement; resource room placement; regular class placement with support services; vocational placement including prevocational services, work-study program, sheltered workshops, activities centers, and community and residential placement; organized recreation; and, special living arrangements. Resources to be used included, but were not limited to, the following:

a. *Diagnostic Center Placements:*

(1) Primary Centers—Arizona Diagnostic, Treatment, and Education Center, Tucson; Arizona Training Programs (Coolidge, Phoenix, Tucson); Vocational Training and Education Program (VTEP), Tucson.

b. *Special Class Educational Placement:*

(1) Primary Centers—Arizona State School for the Deaf and the Blind, Tucson; Public School Special Education classes, Phoenix Day School for the Deaf, ADTEC.

(2) Support Services–Model Demonstration Center, ATP.

c. *Vocational Placement:* Arizona State School for the Deaf and the Blind, Arizona Training Program, Special Education, Public Schools, Vocational Training and Education Program, Community vocational training programs, community job placement.

d. *Sheltered Workshops:*

(1) Primary workshops–Arizona Training Center, Tucson Goodwill Industries (local), Beacon Foundation for the Mentally Retarded.

e. *Activities Centers:* Community Outreach Program for the Deaf; others, to be identified.

f. *Home and Hospital Services:*

(1) Primary Resources–Center for Hearing Impaired Children (CHIC); Model Center staff; Arizona Department of Economic Security; University of Arizona Medical Center; others, to be identified.

g. *Parent and Infant Instructions:*

(1) Primary Programs–Model Demonstration Center, central staff (Mobile Field Unit), Arizona Diagnostic, Treatment, and Education Center, Arizona Training Program, Center for Hearing Impaired Children, Gomper Rehabilitation Center.

h. *Community and Residential Placement:*

(1) Primary Community Placement Resources–Arizona Department of Economic Security, Community Outreach Program for the Deaf (half-way house, private homes).

(2) Primary Residential Placement Resources–Arizona Diagnostic, Treatment, and Education Center, Arizona Training Program (Coolidge, Phoenix, Tucson).

i. *Organized Recreation:* Arizona Diagnostic,Treatment, and Education Center, Arizona Training Program, Community Outreach Program for the Deaf.

j. *Special Living Arrangements:* Arizona Department of Economic Security, Community Outreach Program for the Deaf.

h. *Program Operation.* The wide array of diagnostic, training, education, and support services described above were to be coordinated and administered in the following manner:

A. *Model Demonstration Program Concept.* Undergirding the service approach to be used was the conceptualization of the Model Demonstration Program as a constellation of major service programs rather than a single effort. As pointed out earlier, no single program could adequately meet all the needs of hearing impaired mentally retarded individuals. While such a program could be developed, the cost would be prohibitive. Utilization of available services with the addition of selected new programs could meet the needs of HIMR persons in an effective and economical manner. Thus, the Arizona Model Demonstration Program was actually to be a closely coordinated constellation of programs.

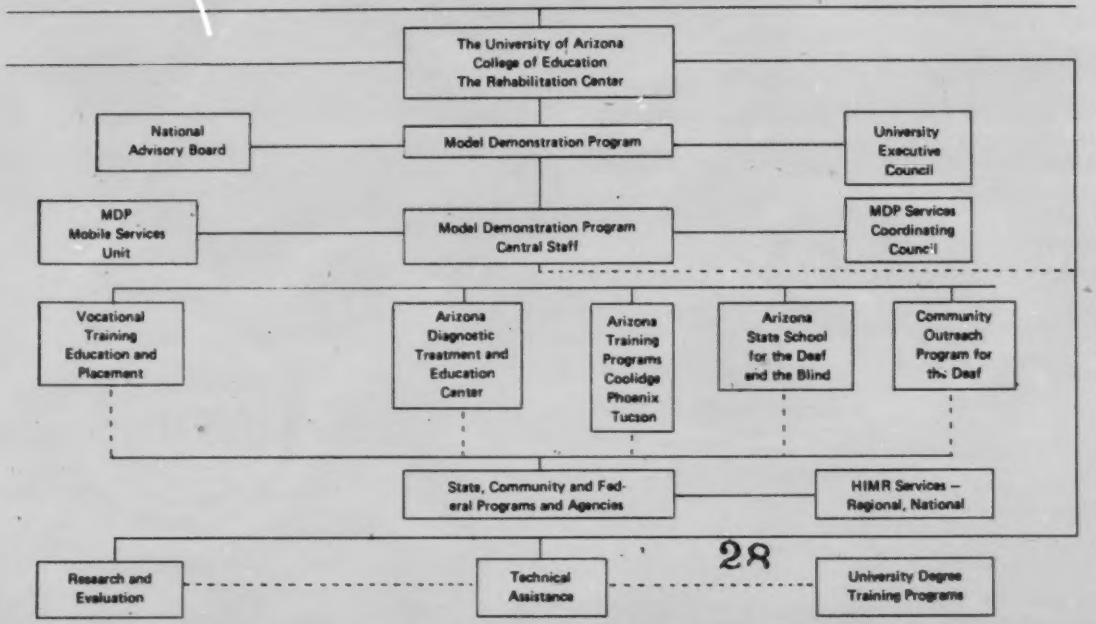
B. *Center Administrative Organization.* The Model Demonstration Program was to be composed of the following programs: Arizona Diagnostic, Treatment, and Education Center; Arizona Training Programs (Coolidge, Phoenix, Tucson); Arizona State School for the Deaf and the Blind; Vocational Training and Education Program, Tucson; and, Community Outreach Program for the Deaf. The heads of services for the HIMR at these programs were to serve as assistant project directors, and were to assist in planning program coordination by serving on the Model Program's Services Advisory Council. Other service agencies were to be viewed as a Model Program support system, with any service agency invited to send a representative to attend the Services Advisory Council meetings. In addition to this Council, there were to be a University Executive Council and a national Model Program Advisory Board. The University Executive Council would advise the project director regarding the University of Arizona's involvement in the project. The National Advisory Board would provide guidance in the implementation of the total project, with special attention to national application of project findings. The administrative organization as projected is presented schematically on the following page.

C. *MDP Central Staff.* The central staff of the Model Demonstration Program was to consist of a Project Director, Research and Training Coordinator, Instructional Curriculum Coordinator, Instructional Media Coordinator, secretary and clerk. The Central Staff was to provide services in the areas of program development, services coordination, support services, technical assistance, professional training, curricula design, instructional media, research, and program evaluation. In carrying out these functions, the staff would work closely with major and secondary system agencies as well as directly with HIMR persons and their parents whenever appropriate.

TABLE 3

ADMINISTRATIVE ORGANIZATION CHART

MODEL DEMONSTRATION PROGRAM FOR THE HEARING IMPAIRED MENTALLY RETARDED IN ARIZONA


The University of Arizona
College of Education
The Rehabilitation Center
National Advisory Board
Model Demonstration Program
University Executive Council
MDP Mobile Services Unit
Model Demonstration Program Central Staff
MDP Services Coordinating Council
Vocational Training Education and Placement
Arizona Diagnostic Treatment and Education Center
Arizona Training Programs Coolidge Phoenix Tucson
Arizona State School for the Deaf and the Blind
Community Outreach Program for the Deaf
State, Community and Federal Programs and Agencies
HIMR Services -- Regional, National
Research and Evaluation
Technical Assistance
University Degree Training Programs

D. *MDP Cooperating Agency Staff.* In addition to the MDP Central Staff, cooperating agencies would provide the facilities and staff that currently were serving HIMR persons. Additionally, through the project, HIMR services would be expanded as follows:

MDP PROJECTED FUNCTIONS

Functions	ADTEC	Staff Resource Team	Administrative Staff
Diagnosis	X_1	X_1	
Education	X	X_1	
Training	X_1	X_1	
Professional Training	X_2	X_2	X_1
Administration	X_2		X_1
Research Coordination			X_1
Technical Assistance	X_2	X_2	X_1
Curriculum Design	X_1	X_2	X_1
Services	X_1	X_1	X_2
Media Development	X_2	X_2	X_1
State HIMR Registry			X_1
Coordination			X_1

Note: X_1 = Primary resource
X_2 = Secondary resource

a. *Arizona Diagnostic, Treatment, and Education Center.* ADTEC was to make its existing facilities and personnel available to the project. Personnel expansion via the project would be: one pre-school teacher, one teacher for school-age children, one teacher for adolescents, one audiologist, one resource teacher, two counselors, and eight educational aides (one for each teacher, and four for around-the-clock care of the children).

b. *Arizona State School for the Deaf and the Blind.* The two counselors, one resource teacher, one educational aide, and the audiologist would provide regular support services to programs for adult HIMR services in various agencies including COPD, ATP, and public school programs.

E. *Professional Training.* The dissemination of knowledge and preparation of experts in the area of serving HIMR persons was to be a major component of the project. This was to be accomplished through graduate and undergraduate degree level studies. Short-term training activities for agency staff as well as HIMR workers from the region and nation were to be conducted on a scheduled basis.

Initially, the College of Education was to employ one faculty member to coordinate research and training efforts. This person would have a joint faculty

appointment with the Rehabilitation Center and the Department of Special Education. First year degree training efforts would focus upon the areas of special education, rehabilitation, audiology, and nursing. Subsequent efforts would broaden to encompass areas such as psychology, educational psychology, and others as appropriate. The Department of Special Education would assign one of its present faculty members on a half-time basis to assist with preparing teachers for the HIMR. The Rehabilitation Center would also assign one faculty member to assist with preparing rehabilitation counselors with the deaf (RCD) to work with the HIMR. Short-term training and staff orientation was to be managed by the MDP Central Staff, with assistance from the Rehabilitation Center and Special Education faculty members. The College of Medicine was to assist as appropriate.

The major thrust of short-term training was to be as follows:

(1) Orientation to the project for participating agency staff

(2) Orientation to the project for supporting agencies

(3) In-service training for participating agency staff to upgrade skills in serving HIMR persons

(4) Information dissemination conferences with regional and national individuals and groups involved with HIMR persons

(5) Training workshops for regional and national individuals and groups for the purpose of upgrading staff skills and program design as well as curricula and training materials used in individual HIMR programs.

F. *Technical Assistance.* The project staff was to be involved in providing technical assistance to professionals serving HIMR persons in the adjacent states of Nevada, Utah, and Texas, and also throughout the nation, as appropriate, in terms of staff workload and demand. This technical assistance was to cover the areas of population identification, developing state registries, program design, curricula, instructional media, personnel, funding, program evaluation and research. This technical assistance was, of course, to be available to agencies within Arizona. Project planners recognized that the multiplier effect was crucial to the success of the MDP project, and this recognition was to be translated into a heavy emphasis on the provision of technical assistance to others.

G. *Regional Status.* In planning this proposal, project planners considered the viability of having a MDP that would bring in HIMR persons from other states for services within Arizona. However, in view of the purposes of the project, funding considerations, legal issues, and facility capacities, the decision was made to not attempt to bring out-of-state HIMR persons into Arizona for services under ordinary circumstances. Instead, the regional component would consist primarily of technical assistance and professional training. In some instances, adult HIMR persons would be able to participate in prevocational training programs under sponsorship of the person's Vocational Rehabilitation Agency or another resource.

The states of Nevada, New Mexico, Utah, and Texas (West) were identified as the region to be served by the Arizona MDP on the basis of apparent need and proximity. A larger area would make travel prohibitive in terms of cost; a smaller area would lessen the multiplier effect.

H. *Field Unit Services (FUS).* An important component of the project was to be a Field Unit Services (FUS) mobile evaluation and basic services unit. The FUS was to be manned by an audiologist, teacher, and teacher aide, transported by a well-equipped van.

Services were to include audiometric screening, psycho-educational screening assessments, support services to HIMR persons in rural communities, parent education and guidance, and technical assistance to health care workers and public school personnel, among others. FUS personnel were to be involved in other service activities within the project at such times as field activities were not in demand.

A major function of the FUS was to be population identification. The unit would visit institutions for the mentally retarded, workshops, institutions for the mentally ill, special education classes in public schools, and other facilities for the purpose of screening for hearing impairment in combination with mental retardation. In the course of such visits the FUS staff was to disseminate information regarding the MDP, HIMR persons, and the system of services available to HIMR persons. Public education efforts were to be stressed. The FUS was to be especially important in effecting the delivery of services to rural areas in Arizona. There are two major population areas in the state, the Phoenix area and the Tucson area. The rest of the state is made up of small towns and villages, with vast distances in-between. There were Indian tribes that had HIMR persons who were not being adequately served, and a large Spanish-speaking population within Arizona was another group needing assistance. The FUS was to be a major factor in effecting services delivery to these people.

I. *Numbers to be Served.* The numbers of hearing impaired mentally retarded persons to be provided with a variety of direct services in the first year was projected at 20 in the following four (4) age groups:

a. *Preschool* (infancy to age five years)
b. *School Age* (age six through 12 years)
c. *Adolescents* (age 13 through 17)
d. *Adults* (age 18 on)

Thus, for the first project year a total of 80 HIMR persons from infancy through adulthood were to receive direct services through the project. Approximately 15 HIMR persons (4 preschool age, 5 school age) would be enrolled in the ADTEC component and 6 HIMR persons would be enrolled in the ASDB component for continuing education, training, and support services. The others would be enrolled at ATP and at other sites.

The estimate of 80 HIMR persons to be served did not include many who had not yet been identified. The total number of new persons was difficult to project, but a conservative estimate was approximately 60 to 100 the first year.

The student/client numbers to be served in the three years of the project was estimated at:

Year	New Preschool	New School Age	New Adolescents	New Adults	Total Number
One (76-77)	20	10	20	20	80
Two (77-78)	10	10	10	10	40
Three (78-79)	10	10	10	10	40
Cumulative (76-79)	10	10	10	10	40
	40	40	40	40	160

It was stressed that these numbers represented the population to be studied for research and development purposes (curricula, media, diagnosis, services). The total three year number of 160 was to consist of HIMR persons of all ages living in a variety of circumstances and receiving a wide range of services. A significantly larger number of HIMR persons besides the target 160 would receive various services through the coordinated system of services.

J. *Personnel Training Participants.* The number of personnel to be trained through the project was projected as follows:

TRAINING PARTICIPANTS

Nature	1976-77	1977-78	1978-79	Total 1976-79
Long Term				
Rehabilitation	2	2	2	6
Special Education	2	2	2	6
Nursing	1	2	2	5
Audiology	1	1	1	3
Psychology	1	1	1	3
Other	1	2	2	5
Subtotals	8	10	10	28
Short Term				
Program Orientation (local)	100	50	–	150
Needs Assessment Workshop	25	25	25	75
Population I.D. Workshop	25	25	–	50
Program Development Workshop	25	25	–	50
Curricula Workshop	20	20	20	60
Instructional Media Workshop	30	20	20	60

Short Term (Cont.)	1976-77	1977-78	1978-79	Total 1976-79
Services Delivery Workshop	30	20	20	70
Regional Information Dissemination Workshop	–	–	50	50
National Information Dissemination Workshop	–	–	100	100
Subtotals	255	185	235	675
GRAND TOTALS	263	195	245	703

It was noted that the initial workshops would be for professional workers within Arizona, with later workshops for regional and national workers. Participants were to be reimbursed by their employing agency for attendance at most workshops; several of the workshops would have participants reimbursed for their expenses by the project.

The professional training component was to provide traineeship stipends to degree seekers.

K. *Project Facilities.* Facilities for this project were to consist of administrative, services, and residential components.

a. *Administration.* The project staff was to be headquartered in a mobile housing unit erected adjacent to the existing ADTEC Building on the campus of the Arizona State School for the Deaf and the Blind. This location would facilitate optimal communication with service units. Long-term training personnel were to have an office at the College of Education complex at the University of Arizona. Other staff would be placed within specific agencies as described previously in section 3.A. (4)d. These agencies would provide office and activities space.

b. *Services.* The facilities to be used for services were described in section 3.A. (3).

c. *Residence.* Residential components were described in section 3.A. (3).

1. *Curricula Development.* This component was to be a major part of the project. Efforts were to be centered around application of innovative individualized instructional approaches with hearing impaired mentally retarded individuals, following individual growth and development during the education and training process, documenting processes and outcomes, and articulating the activities and materials utilized. Curricula would be developed for preschool HIMR children, school-age HIMR children, HIMR adolescents, and HIMR adults. Diagnostic and education/training/services procedures were to be closely integrated and their relationships documented for the curricula. The agencies to be involved utilized an individualized instruction approach based upon diagnositc data; but curricula had not been well-articulated. The project was to focus upon studying and identifying

input, process, and output components that are appropriate for an effective curriculum for a given age range for specific groups of HIMR persons (e.g., mildly, moderately, and profoundly mentally retarded, with varying degree of hearing loss). As will be described later, the curricula to be developed was to have its base in diagnostic procedures and reassessment procedures.

M. *Diagnostic Procedures.* The following diagnostic procedures were to be utilized with HIMR individuals.

a. Standard audiometry
b. Special audiometric procedures
c. General and specialized medical assessment
d. Psychological assessment
    (1) Standardized testing
    (2) Situational assessment
e. Family and social variables
f. Educational assessment
g. Self-care skills
h. Vocational assessment
i. Skills in independent living
j. Other, as required in individual cases.

ADTEC had purportedly developed and utilized a comprehensive diagnostic system with its sensory-impaired multiply handicapped children population. A computer system processed diagnostic data, and the results were used under an "optimizing" technique whereby behavioral deficiencies were identified and had become the focus of education/training/services efforts. A student monitoring system had been charted and was utilized as a flow system for the provision of services.

N. *Research Efforts.* Project research efforts were to be coordinated by project staff, working in close collaboration with appropriate faculty members from the University of Arizona and personnel from the various cooperating service agencies.

Research activities were to concentrate on the process for development of awareness and services for HIMR persons, in a comprehensive, coordinated network of helping agencies. This was to include elements of public awareness, levels of preparation, needs assessment, and resource identification and utilization. Precise definitions of available services would be generated for linkages with the various needs of the HIMR. Service gaps and overlaps would be considered by the cooperating agencies in an effort to develop the most effective service delivery system.

New approaches were to be explored for early screening, diagnostic assessments, prescriptive instructional and habilitative programs, recreational services and general social and self-development. Self-reliance and sufficiency were to be stressed as much as possible in order to combat "learned helplessness." Vocational evaluation

and placement, and development of career opportunity concepts for the HIMR would also be an important part of research activities. Every effort was to be made to establish new linkages for training, work experience, and satisfactory employment opportunities.

In addition to research concerned with different aspects of comprehensive, coordinated HIMR services, targeted research was to consider the impact of mental retardation on hearing impairment, and vice versa. Specific interdisciplinary studies would attempt to create new knowledge in this area.

Research topics and thrusts were to be defined by the University Executive Council, the Services Advisory Council and the National Project Advisory Board as the MDP project evolved. Initially, they were expected to include:

a. Physical, psychological and social characteristics of HIMR persons
b. Work adjustment training techniques with HIMR young adults
c. Training techniques for preparing HIMR persons for independent living in the community
d. Techniques for assessing the psychoeducational potentials of HIMR children
e. Incidence of HIMR among minority populations (Indians, Chicanos)
f. Techniques of counseling with HIMR young adults
g. Etiological correlates of HIMR
h. Procedures for establishing a state registry for HIMR persons
i. Optimal teaching/learning situations and methods for the HIMR
j. Minimum skills for independent and sheltered living for HIMR persons
k. Assessment/development of vocational areas most suitable for HIMR persons
l. Intelligence, hearing loss and educational achievement

O. *Accelerating, Decelerating Factors.* The factors that would accelerate the progress of the project included timeliness of the grant award and availability of personnel for filling positions. Problems in either area could delay the project. However, then-present prospects for professional recruitment appeared to be encouraging.

P. *Unusual Features of the Project.* This project was considered unusual in that Arizona had an exceptional level of interest and involvement in deafness rehabilitation and education. The University of Arizona had a long history of participation in preparing personnel to serve deaf persons and mentally retarded persons. Arizona's rehabilitation services had recently expeanded on behalf of deaf people. The deaf community was an active one, and communication between professionals and the deaf community was excellent. Serving multiply handicapped deaf persons had increased in importance, as reflected in the new ADTEC program and the services being offered to the deaf-blind in Arizona. Arizona had several professionals possessing long experience in various phases of education and rehabilitation of the deaf and mentally retarded. The University of Arizona Medical Center and College of Medicine had expressed exceptional support of this project and would be involved in its operation in important ways. State and local government agency interest was also at a high level.

Under consideration at the time was the feasibility of collaborating with the Utah University-Affiliated-Facility (UAF) center to explore UAF satellite status for the Arizona Model Demonstration Program for the HIMR. It was hoped that UAF satellite status would become a reality in the near future.

Finally, the ADTEC diagnostic process was expected to offer an extremely innovative attempt to quantify, analyze, and apply specific materials and techniques for assessing the abilities and needs of multiply handicapped sensory-impaired children. A computer system was to be used to analyze data, and systems were available for programming treatment based upon diagnostic data. Heriot (1973, 1974) had developed a method for utilizing the Peabody Picture Vocabulary Test for differential diagnostic purposes, including diagnosis of oral reading skills and non-oral reading skills. It was planned that Heriot's concepts and procedures would be further tested and applied specifically with hearing impaired mentally retarded children, youths, and adults.

5. *Evaluation Strategies* Evaluation activities were to be specifically designed to relate to the various milestones. Three types of evaluation strategies were to be employed:

a. *Situational:* efforts to further define and isolate the various component elements of addressing HIMR needs and services.

b. *Process:* comparisons of actual procedural activities to those outlined; analysis of the effectiveness and timeliness of item events; and, constant review of possible modifications to the timetable or specific targeted milestones in order to maximize MDP effectiveness and impact.

c. *Impact:* analysis of actual changes in HIMR needs, awareness and services as compared to the MDP objectives as outlined in Part IV, page 1.

Specific evaluation activities were to be further developed as the project staff and advisory bodies became organized. Documentation of alternatives considered, as well as detailed reporting of evaluation approaches taken, would be rendered for the Office of Human Development, as well as for use by other states/regions interested in possible replication of these efforts.

6. *Key Participants, Cooperators and Advisory Bodies.* The following agencies, organizations and individuals were expected to become involved in the MDP project;

a. University of Arizona, including representation on the University Executive Council:

Arizona Health Sciences Center
Department of Business and Career Education
Department of Psychology

Department of Special Education
Department of Speech and Hearing Sciences
Rehabilitation Center
School of Nursing

b. Various State of Arizona agencies and organizations, including representation on the Services Advisory Council:

Arizona Department of Economic Security
- Services for the Blind and Visually Impaired
- Vocational Rehabilitation
- Food Stamps
- Welfare
- Department of Mental Retardation, including the Arizona Training programs in Coolidge, Phoenix and Tucson

Arizona Developmental Disabilities Office
Arizona Diagnostic, Treatment and Education Center, Tucson
Arizona State School for the Deaf and the Blind, Tucson
Arizona White House Conference on the Handicapped
Bureau of Child Development, Children's Hospital
Community Outreach Program for the Deaf, Tucson
Indian Health Services
Maternal and Child Health, Phoenix
Mental Health Department
Special Education program in public school systems
Speech and Hearing Clinics

c. National Project Advisory Board:

Dr. Samuel Kirk - University of Arizona Mental Retardation Education
Dr. Edna Adler - Rehabilitation Servies, HIMR
Dr. Robert Lennan - California School of the Deaf (Riverside)
Dr. Marc Gold - University of of Illinois, Vocational Training and Mental Retardation

Representatives from:

A.G. Bell Association for the Deaf
American Instructors of the Deaf
Conference of Executives of American Schools for the Deaf
American Association for Mental Deficiency

7. *Geographic Location.* The project was to be centered in Tucson, Arizona with major work carried out within the State of Arizona and the adjacent states of Nevada, New Mexico, Utah and West Texas. Technical assistance was to be available on a national basis.

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CHAPTER 3

ESTABLISHMENT AND OPERATION OF THE MODEL DEMONSTRATION PROGRAM: ADMINISTRATIVE ASPECTS

Chapter 2 presented the *proposed* Model Demonstration Program for Hearing Impaired Developmentally Disabled Persons; program goals and methodology were described in hypothetical or tentative fashion. This chapter and the chapters to follow will report what actually happened in the development and operation of the Model Demonstration Program. Chapter 3 focuses upon administrative aspects of the project that are of concern to planners who may wish to initiate a similar program.

ORGANIZATION

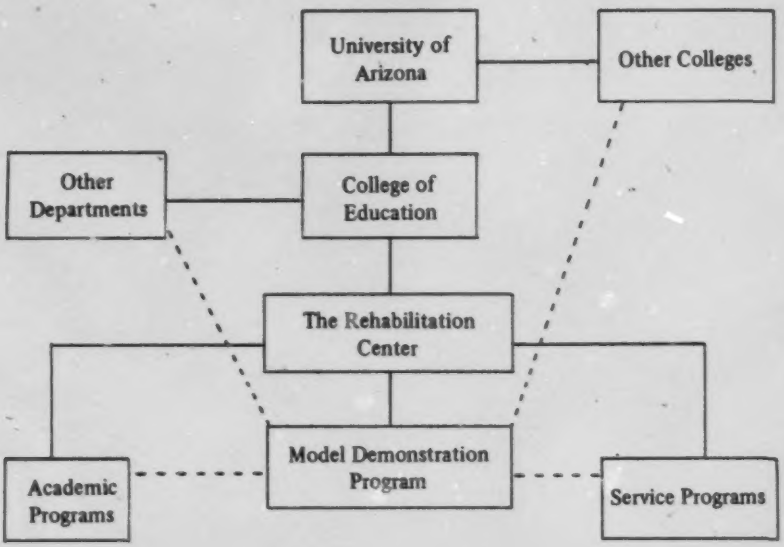
The Model Demonstration Program was organized administratively within the Rehabilitation Center, an academic and services department within the College of Education of the University of Arizona, Tucson. The Rehabilitation Center offers undergraduate and graduate training in rehabilitation-related fields, and operates research and service programs as adjuncts to such training. For many years the Rehabilitation Center has offered specialized degree training in the rehabilitation of the deaf as well as short-term courses and workshops in the area of interpreting for the deaf. From 1973 through June, 1976, a special demonstration project, funded by the Rehabilitation Services Administration (HEW), was carried out. It was designed to develop model systems for the delivery of community services to deaf persons (Turechek and Stewart, 1976). These and other experiences (for instance, The Rehabilitation Center co-hosted the 1974 Conference of the Professional Rehabilitation Workers with the Adult Deaf) were held in Tucson.

The College of Education's Special Education Department has for years offered separate degree training in the education of the deaf, the education of the mentally retarded, and the education of the multiply handicapped.

The Arizona Health Sciences Center, with prominent programs in the medical and allied health sciences fields, was another strong resource within the University of Arizona.

Hence, establishing the project within the University of Arizona, and in the College of Education in particular, was a logical decision. This placement enabled the project to have relatively ready access to many university resources.

The following schematic display illustrates the organization of the Model Demonstration Program within the University:



Under this organization, the administration of the project was implemented through normal University channels and with project access to resources throughout the University. The project director and other project staff were employees of the Rehabilitation Center, and personnel, payroll, accounting, purchasing, and benefits were processed through the University via the Rehabilitation Center.

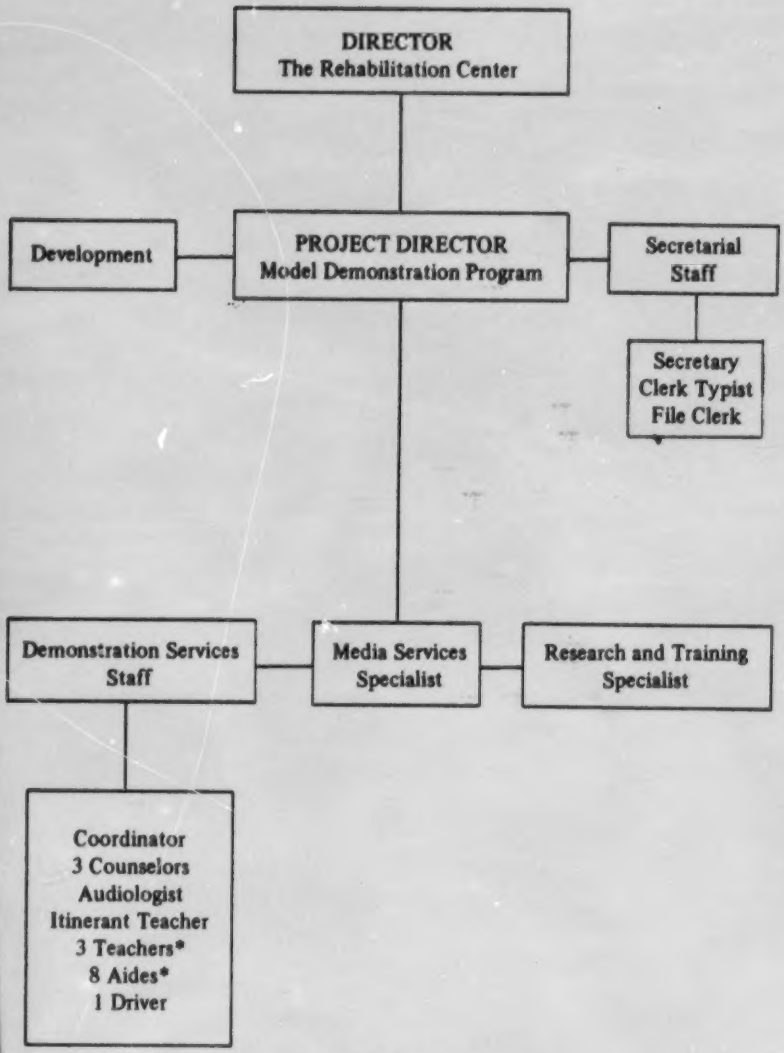
The HEW grant award provided an indirect cost allowance of 37% TDC (total direct costs) to the University for carrying out the Model Demonstration Program during the first and second year of the project. The third year indirect cost allowance was reduced to 8% to reflect the final year's emphasis upon training (as opposed to services) activities.

The University's funding contribution to the project was set at 10% of the total federal grant award, and such contribution, as it turned out, came in the form of "in-kind" contributions (faculty time contributions) and third-party contributions (office space, utilities, and maintenance; personnel time; consultation).

Within the project, the following functional organization was effected for the first year (see chart 1);

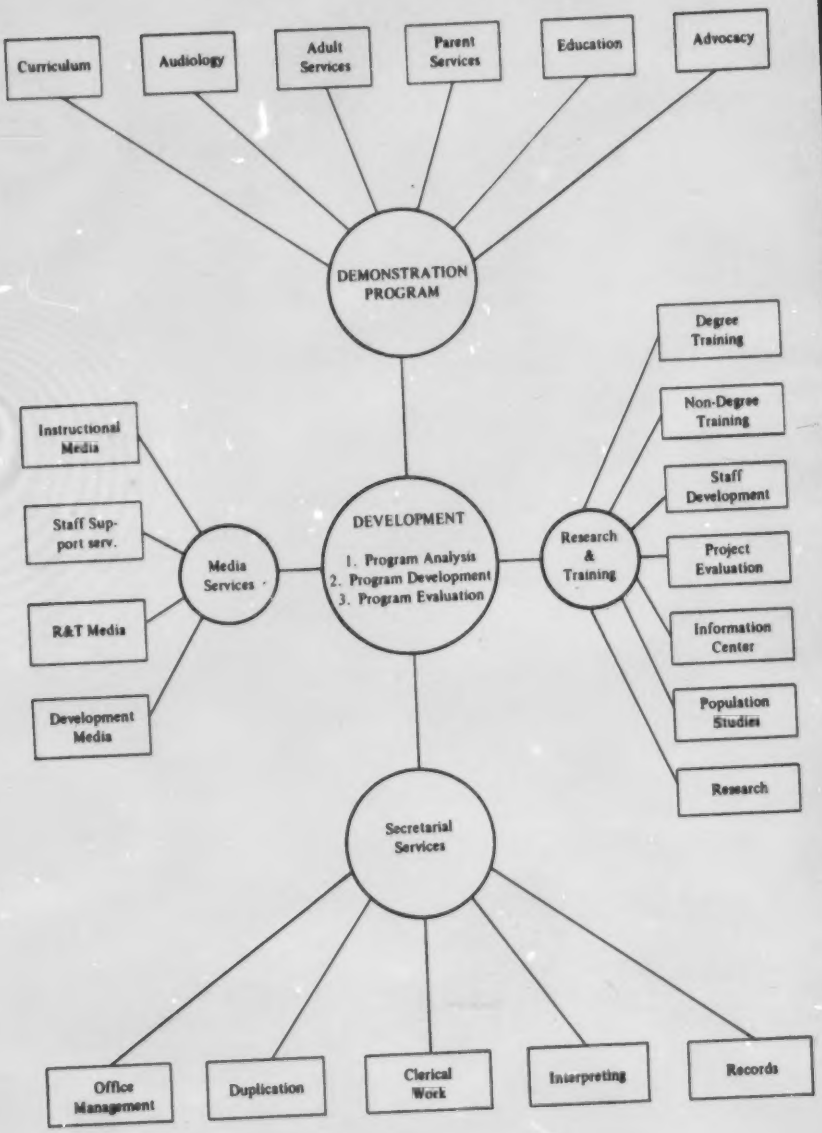
The operational organization of the project is illustrated in chart 2:

CHART 1
Staff Lines of Supervision



*Supervision shared with ADTEC during first year.

CHART 2
Operational Organization of
The Model Demonstration Program



Advisory Committee. The project was set up to operate with input and output from three separate advisory committees. A University Executive Council was established to assist the project director in identifying priorities, in effecting interdepartmental cooperation on behalf of the project, and in dealing with the seemingly inevitable "growing pains" of a new project within a large organization. Members of this council were:

Dr. Willis Brewer, Office of the Vice President, Arizona Health Sciences Center
Dr. George Leshin, Head, Department of Special Education
Dr. Karen Newman, Professor, Department of Special Education
Dr. Amos Sales, Director, The Rehabilitation Center*
Mr. Richard Saltford, Special Projects, Office of the Dean, College of Education
Dr. Paul Skinner, Head, Speech and Hearing Sciences
Dr. David Wayne Smith, Office of the Vice President, Allied Health Sciences Center
Dr. Marsden Stokes, Director, The Rehabilitation Center**
Dr. Armin Turechek, Professor, The Rehabilitation Center

* 1977-79
** 1976-77

A Services coordinating Council was established to provide initial input to the project in organizing its coordinated system of client/student services. Membership consisted of the following:

Ms. Carol Albrecht, Planner
Arizona Development Disabilities Planning and Advocacy Council

Mr. Ron Barber, District Manager
Arizona Bureau of Mental Retardation

Ms. Anita Blake, Supervising Teacher for the Deaf
Adaptive Education Program
Tucson Unified School District

Dr. Willis Brewer, Assistant
Office of the Vice President
Arizona Health Sciences Center

Dr. Ralph Hoag, Superintendent
Arizona State School for the Deaf and the Blind

Ms. Jonna Miller, Supervisor
Sensory Training Unit
Arizona Training Program, Coolidge

Dr. Dan Overbeck, FAAMD
Private Psychologist

Mr. Norm Rash, Coordinator
Services for the Deaf
Arizona Bureau of Rehabilitation Services

This council functioned on an *ad hoc* basis the first year, with subsequent activities in the coordination area transferred to ongoing advisory groups in the State of Arizona such as the Arizona Advisory Council for Deaf/Blind Persons (AACDBP) and the Division of Development Disabilities/Mental Retardation Services Task Force on Sensory Impairments.

A National Advisory Committee (NAC) to the project was formed during the first year and continued to provide input to the project over the three years of the project via annual meetings in Tucson. The membership of this committee consisted of:

Mr. Wallace K. Babington, Director
Office of Information & Resources for the Handicapped
Office of Human Development Service
U.S. Department of HEW

Mr. Dennis DeConcini
U.S. Senator from Arizona

Dr. William Healey, Director
School Service Program
American Speech & Hearing Association

Lee Henney, Ph.D.
Director
Educational Materials Center Institute

Dr. Samuel Kirk, Professor
Special Education Department
The University of Arizona

Dr. Robert Lennan, Superintendent
California School for the Deaf, Riverside

Tadashi Mayeda
UCLA/NPI
Pomona, California

Mr. Max Addison, Executive Director
National Association for Retarded Citizens

Roberto Rendon, M.D.
Neurologist

Dr. Frederick Schreiber, Executive Secretary
National Association for the Deaf

S. Richard Silverman, Ph.D.
Director Emeritus
Central Institute for the Deaf
St. Louis, Missouri

This NAC assisted the project in evaluating its progress according to stated goals and provided input concerning alternatives for implementation of activities.

In addition to the above named individuals, consultation regarding specific phases of the work and valuable input at crucial stages of the project was provided by several key persons. Among them were Dr. David Braddock (Austin, Texas), Mr. Doug Burke (El Paso, Texas), Mr. Ralph White (Austin, Texas), Dr. Tom Goulder (Beverely, Mass.), Dr. Dan Overbeck (Tucson, Arizona), Ms. Marsha Mosher (Tucson, Arizona), and Dr. Geno M. Vescori (Huntington Beach, California).

Mr. Max Arrell (Austin, Texas), as a site visitor for HEW in 1978, provided important consultation to the project at a crucial stage of its development.

Ms. Thelma Lucas of the Developmental Disabilities Office (HEW) was a continuing source of valuable guidance and information throughout the project. She and Dr. Richard Johnson of the Office of the Handicapped, Office of the Secretary, were important resources for the project.

Cooperating Agencies, Schools. Informal cooperative relationships were established with quite a large number of schools and agencies throughout the life of the project, with cross referrals of clients and students enhanced through these relationships. Formal, contractual arrangements were reached with two agencies for specific performance objectives. These involved the project and (1) the Arizona Diagnostic, Treatment and Education Center (ADTEC), a facility under the Arizona State School for the Deaf and the Blind, and (2) the Division of Developmental Disabilities - Mental Retardation Services, Arizona Department of Economic Security.

The ADTEC contract provided for the establishment of a special program for HIDD children within the on-going ADTEC program, as proposed in Chapter 2. This agreement, which was made initially on a Fiscal Year basis, with the first year to end September 30, 1977 (in consonance with the ending of the first grant award year of the Model Domonstration Program), was intended to continue for the duration of the three-year project. However, implementation of the agreement over the course of the initial year was inefficient for a variety of reasons of an administrative nature, and as a consequence the agreement was terminated effective 9/30/77.

The agreement with the DDD/MRS involved the cooperative use of the Model Demonstration Program's mobile evalution unit - a mobile audiological assessment unit constructed especially for the project. This agreement, implemented in 1978-79, called for a systematic screening of DDD/MRS clients in an attempt to enhance identification of HIDD individuals. The agreement provided to be an effective and efficient one, resulting in a high level of performance according to the stated goals of the project. It demonstrated that interagency cooperation can be effectively achieved even in the face of split administrative responsibilities.

Physical Space. Physical space for the project was obtained initially during Year I by locating the "central project staff" (project director, curricular coordinator, clerical staff, itinerant teacher, media specialist, audiologist, counselors, research & training specialist) in offices in a building belonging to the University several blocks away from the main campus, and by placing three teachers and eight teacher aides in classroom space at ADTEC under the previously cited MDP/ADTEC agreement.

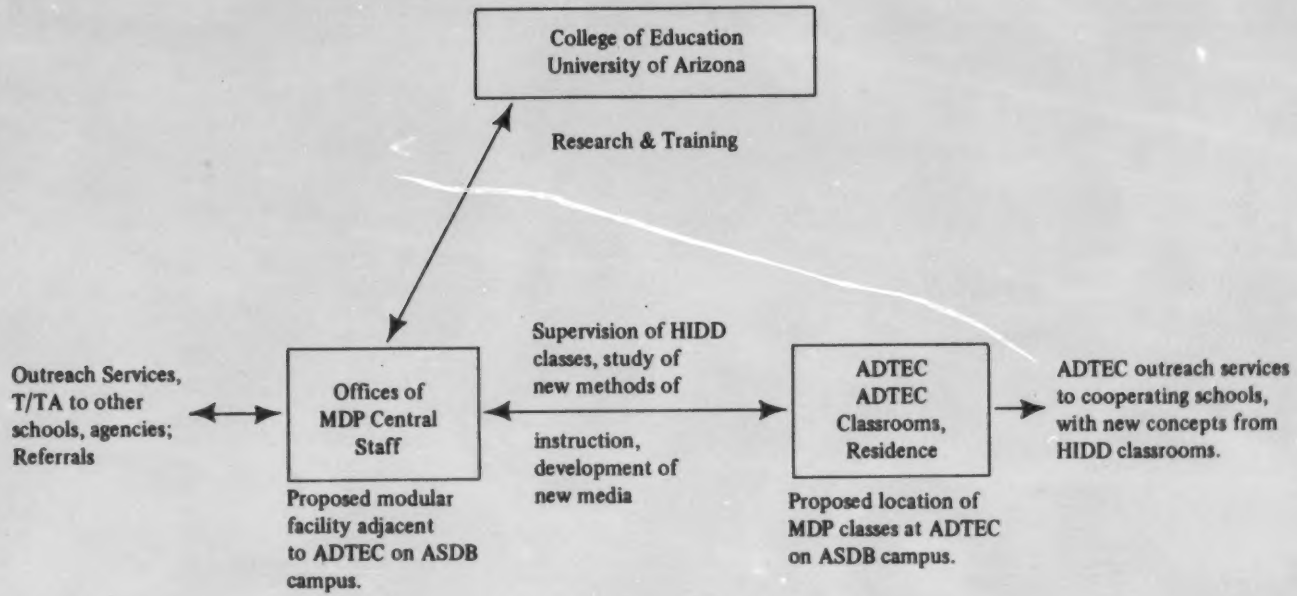
This was not the original plan. When the project was first designed, plans were included to construct a temporary, modular office space unit on the campus of the Arizona State School for the Deaf and the Blind. This unit was to house project staff adjacent to the core demonstration center - ADTEC - which would permit close interaction with demonstration center staff (teachers, aides, etc.) and permit appropriate supervision as well as interaction of service, research, and professional training components. The research and training staff member was to be officed in the College of Education, which would encourage effective interaction between the project and the University. Chart 3, on the following page, is an illustration of this original plan.

When the project was funded, however, and actions initiated to proceed with obtaining the modular office building and other space as described above, several events begin to transpire that eventually stretched over a two year period of time while radically affecting the conduct of the project.

First, enrollment at both ASDB and ADTEC had increased at an unforeseen rate beween the time the project proposal was written and the time the grant award was made. As a result, when an effort was made to initiate the classes at ADTEC there was a severe space crunch leading ADTEC administrators to request that the modular unit be designed, constructed, and used as a classroom rather than as office space. This change was accepted out of necessity, and, as an alternative for office space it was proposed by ADTEC that central project staff be officed within ASDB. The project director and his administrative assistant, the only project employees at the time, elected to be officed near the University instead, since much internal work was anticipated in such areas as developing job descriptions, establishing the positions within the personnel office of the University, recruiting staff, setting up University relations, and procurring the modular building as well as the mobile evaluation unit. Thus, initial project offices started out in temporary University-donated space while a major revision was made in the planned use of the to-be-constructed modular building.

CHART 3

Schemata showing conceptualization of physical space of the Model Demonstration *Program as proposed, and relation of physical space to functions.*


College of Education
University of Arizona
Research & Training
Outreach Services, T/TA to other schools, agencies; Referrals
Offices of MDP Central Staff
Proposed modular facility adjacent to ADTEC on ASDB campus.
Supervision of HIDD classes, study of new methods of instruction, development of new media
ADTEC
ADTEC
Classrooms, Residence
Proposed location of MDP classes at ADTEC on ASDB campus.
ADTEC outreach services to cooperating schools, with new concepts from HIDD classrooms.

Second, as events unfolded there were unexpected complications with such questions as responsibility for the modular unit (to be owned by the University but situated at ASDB), the procedures for inviting bids for the unit (who should supervise this - the University or ASDB?), how to arrange for increases in the cost of the unit due to the modified design as required to make it a classroom/residence unit, and how to initiate project classroom activities while awaiting construction of the modular unit? All of these complications were further intensified by the fact that regardless of what was agreed upon in connection with the modular unit and classes, project-sponsored activities at ADTEC (the recruitment and hiring of teachers, aides; purchase of instructional equipment and supplies) could not begin until a formal contractual agreement had been authorized and signed by ASDB and by the University's Board of Regents as well as by the State Attorney General!

In the face of these confusing, difficult legal issues, certain decisions had to be made in an untimely manner because of the emergence of political pressures placed on the project as a consequence of actions by some disappointed applicants for the project as a consequence of actions by some disappointed applicants for the project who had lost out in the RFP process. Pressure was applied to the project to hire staff, get classes into action, and begin other project activities immediately. As a consequence, an inadequate situation presented itself whereby insufficient time was available for careful, well thought through planning in the face of the necessity to modify use of the modular unit.

As matters worked out, subsequent changes took place producing the following outcomes;

1. In January, 1977, the ADTEC classes and residence area for HIDD children had to be housed in the ADTEC buildings despite the crowded conditions, and due to this placement project-sponsored teachers and aides were supervised by ADTEC personnel rather than by project personnel as previously planned.

2. Bids for the modular unit were not processed in a timely manner due to all of the legalities involved. As a consequence, central project staff had to be relocated in more convenient office space, secured by the project director through the Arizona Training Program at Tucson - which was located 10 miles away from ADTEC but which was the only option available after it was discovered that neither the University nor ASDB had office space for housing all of the central project staff.

3. The experience gained during the first year of the project resulted in a decision to locate the modular unit at the Arizona Training Program in Tucson rather than at ADTEC. This was considered to be a feasible move since (a) delays had resulted in a failure by the contractor to build the unit at ADTEC, and (b) the first year cooperative arrangement with ADTEC had not produced the results requested by the project.

4. The contractor, who submitted the low bid for the modular unit and who was awarded the contract by the University, was extremely slow in completing the

blueprints for the unit, and later had its design rejected by the State. By the time the design was finally approved, the contractor had lost its license due to court litigation on other matters, and subsequently defaulted in constructing the modular unit. By this time, the project was halfway through the three-year period, so plans for the modular unit were set aside.

5. Ultimately, the project ended up conducting its own demonstration classes during the second project year within donated space on the campus of the Arizona Training Program, Tucson. This permitted operation of the project in a strong center for the developmentally disabled, even though the program had to be managed fully by project staff.

Summarizing the physical space situation, the project failed to obtain its anticipated space *or* the planned modular unit. However the project was kept on course and eventually arrived at a point where space was available and in use by project staff and students at ATPT. The entire physical space issue was a major headache for all concerned, and this issue should be considered very carefully in any future projects of this nature.

Personnel Recruitment. The area of staff recruitment and employment was another major administrative problem. The project grant award arriving in October, 1976, was untimely insofar as staff recruitment was concerned. Few qualified persons were available for employment at that time of year. Recruitment for the top administrative positions was complicated by limitations in salary ranges, and as a result some modifications in job descriptions and qualifications were necessary. By October, 1977, however, the project was fully staffed and had a year of successful activities behind it.

A summative statement regarding the administrative aspects of the Model Demonstration Program would be this: The project was an extremely difficult one to implement, made so by the complex problems of the HIDD population, the short time available (3 years) to do a job that will require decades to complete, the absence of ready parameters for such an endeavor, and the many pressures and special interests to which the project had to respond. Unfortunate circumstances with the modular building and with several personnel recruitment efforts were remedied only by extra efforts, timely assistance from other agencies such as BMR/ATPT. Yet, final outcomes were productive and constructive for HIDD persons. There is a better way, however, and in the Recommendations Chapter this will be described.

CHAPTER 4

SERVICES FOR HIDD PERSONS: IMPLEMENTING INITIAL STRATEGIES AND RATIONALES

Chapters 1-3 have described pertinent aspects of the background, planning, and administrative establishment of the Model Demonstration Program. Chapter 4 presents a description of the initial service, research, and training activities of the project. Also presented is a discussion of the apparent reasons why, in the face of so many convincing arguments in favor of specialized services for HIDD persons and how these can be achieved, so little has actually occurred in the past regarding the establishment of such special services.

Part I: Initial Services of the Project

By December, 1976, a core project staff had been recruited consisting of project director, administrative assistant, typist, two counselors, an audiologist, a research and training specialist, a teacher consultant/educational diagnostician, and a media specialist. Due to the facility acquisition problems cited in Chapter 3, these staff members were headquartered in offices adjacent to the university campus until March, 1977. During this same time, ADTEC had employed the team of teachers and teacher aides as required for the three project demonstration classes located in the ADTEC facilities.

Through these two staff complements, the project was able to initiate its developmental efforts in the areas of outreach services, demonstration activities in curriculum and media, population identification, coordination of services, T/TA services to existing programs, and research related to these activities.

In March, 1977, a Coordinator of Curriculum Development was hired, and by the end of the month the central staff had relocated in what turned out to be permanent office space on the campus of the Arizona Training Program in Tucson.

The initial functions of these two project staff complements were as follows:

Central Staff. The central staff devoted its beginning efforts to:

1. Identifying schools, agencies, and organizations offering services to hearing impaired persons, to developmentally disabled persons, and to hearing impaired/multiply handicapped persons.

2. Operationalizing the goals, objectives, and methodology of the project.

3. In-service training for the purpose of developing a common understanding of goals, procedures, and policies for the project staff.

4. Identifying cooperating programs and setting up cooperative agreements.

5. Conducting basic studies of current services and coordinating mechanisms in the state.

6. Setting up data collection systems.

7. Designing the mobile evaluation unit and planning its use.

ADTEC Complement. The project staff employed under ADTEC went through in-service training to learn the ADTEC system, placed appropriate HIDD children in the three demonstration classes, and implemented instructional efforts with these children according to the ADTEC model of individualized instruction (See Chapter 2).

Issues to be Solved. As the project staff moved further into the planning stage for implementing its program of activities for the three-year period, several fundamental issues surfaced that required answers and decisions on the part of the project staff. These issues are summarized below:

1. Initially planned and approved by HEW as a project addressing the hearing impaired mentally retarded population, HEW had subsequently - two months after grant award - requested that the project address the needs of the entire hearing impaired developmentally disabled (HIDD) population. How was this greatly expanded focus to be operationally achieved with no change in funding or time allowance?

2. With such a broad mandate - to address the needs of HIDD children and adults - what sequential steps could be taken to better define the population and systematically organize an effective chain of coordinated services among a wide variety of public and private agencies, schools, and organizations designed to respond to their needs?

3. Given the then-current limited information regarding HIDD population prevalence rates and demographic characteristics, what could be done to obtain more definitive knowledge?

4. With the persistent, unexpected problems of obtaining facility space in a timely manner, what steps should be taken to initiate meaningful demonstration class activities?

5. Related to Question One, but also relating to the broader issue of "chain of services," how could the project, as an "outsider" and a brand-new entity,

systematically plan and orchestrate its activities in order become a viable agent of positive change in on-going service programs and schools with their well-defined "territorial rights"?

6. Finally, a more fundamental, all-pervading question was this: Given that, (a) existing program enabling legislation could have, long ago, resulted in specialized services for *all* handicapped persons, and (b) the fact that general as well as fairly specific program parameters for HIMR persons had been clearly spelled out (Healey, 1975), then why had there, up to the present time, been such minimal programmatic response nationwide? Why had not schools and agencies responded to the Healey (1975) recommendations? More importantly, what could the Model Demonstration Program do to identify the causes of this lack of response and deal with them in such a manner that there would be more positive responses in the future?

The project staff, after several weeks of study, meetings with school and agency heads, and consultation with University Executive Council and Services Advisory Council members, made the following decisions:

1. The project would respond to the HEW mandate to expand the project to cover all HIDD persons by working with schools and agencies serving the autistic, the cerebral palsied, and the epileptic, as well as the mentally retarded. All project service, research, and training would reflect this expansion in focus. *Wideband coverage* would prevail over *indepth coverage*. Chart 4 illustrates this change. As we see, the change reduced the relative stress upon the project's own facility demonstration classes, but increased the emphasis upon helping cooperating schools and agencies to conduct special classes for HIDD persons.

2. The question of handling the problem of coordination of services with HIDD persons would be resolved in the same manner as with services *per se* (i.e., by wideband coverage rather than in-depth coverage).

3. The project would utilize a multiple level approach in obtaining population estimates and empirically conceptualized characteristics-descriptive data derived from actual work with HIDD persons in selected locations.

4. Concerning services, the project staff decided to emphasize model building within the ADTEC component (later transferred to ATPT) as well in other typical settings (public school, an institution - ATP, Coolidge, a group home [the Community Outreach Program for the Deaf], and others). However, only the ADTEC component would be started immediately, with other developments to await the input expected from a statewide needs assessment.

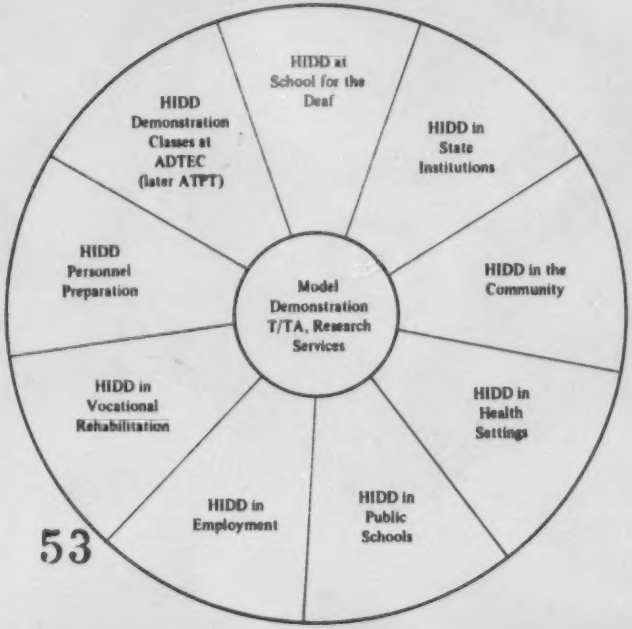
5. Question Five was a most difficult one to answer, but finally the project staff decided to just go ahead and become "a new kid on the block" of service providers, both inviting referrals as well as making them in an aggressive, well-publicized manner, based upon the outcomes of a planned statewide needs assessment which was held later (January, 1977).

CHART 4: Changing from a HIMR Focus to the HIDD Focus.

1. *Proposed* HIMR Focus

HIMR at School for the Deaf
HIMR in State Institutions
HIMR in the Community
HIMR in Health Settings
HIMR in Public Schools
HIMR in Employment
HIMR in Vocational Rehabilitation
HIMR Personnel Preparation
Model Demonstration Program Facility and Outreach Program

2. *Modified* HIDD Focus (Note relative size of inner circle)


HIDD at School for the Deaf
HIDD in State Institutions
HIDD in the Community
HIDD in Health Settings
HIDD in Public Schools
HIDD in Employment
HIDD in Vocational Rehabilitation
HIDD Personnel Preparation
HIDD Demonstration Classes at ADTEC (later ATPT)
Model Demonstration T/TA, Research Services

6. The answer to the most basic question - why so little had been done in the past and what could be done to change this pace - was *suggested* by the needs assessment in January 1977, but did not become *clear* to the project staff until well into the second year of the project. This answer is presented in a later section of this chapter.

Part II: Needs Assessments Pave the Way

The Model Demonstration Program's actual strategies in the research, training, and services areas, were easily conceptualized in the project proposal. The beginning basic program elements, as well as initial staff activities, were not difficult to start. However, just as an effective, well-defined process for assembling an automobile or any other complex operational mechanism depends upon the tools at hand and available physical and human resources, the development of what amounted to new services systems for HIDD persons had to proceed within the limitations and potentialities of the human and programmatic elements existing at the time. Obviously, these elements had to be identified and specified, and consequently doing so became an initial top priority. While planning the project had involved a general needs assessment, implementing the plans required more detailed information.

Accordingly, four related major activities were planned and implemented over a 14 month period of time. This span resulted in a continuing stream of input that slowly but meaningfully affected program content. These activities were (1) a statewide survey of services available to HIDD persons, (2) a statewide HIDD needs assessment, (3) a national survey of State-Department of Education services for HIDD persons, and (4) a national survey of residential schools for the hearing impaired.

SERVICES AVAILABLE TO HIDD PERSONS IN ARIZONA

The project staff designed a questionnaire relating to services for HIDD persons (see appendix I, in back of book), and distributed it in three ways. Initially, individual visits were made to agencies which were known to serve either the hearing impaired or the developmentally disabled, and an interview was conducted. When a sample of 30 was completed and the information analyzed, the survey form was modified and the remaining identified agencies were contacted by mail. (The service providers were identified by Child Find, the Bureau of Mental Retardation, and existing service directories). When the last of the returns were received, agencies which did not respond were contacted by telephone. Accuracy was stressed in all phases of information collection.

This effort led to the publication of *Arizona's Resources for Persons with Hearing Impairment and Developmental Disabilities* (1977). In it, a total of 114 schools, agencies, and organizations located within Arizona were listed and their

services described. The Directory was sent to all of these 114 agencies as well as to others, not listed, that were potential service providers or referral sources.

Among the 114 listed organizations, however, only five (5) operated substantial programs for the education and rehabilitation of the deaf, and these five did not *specifically* serve HIDD persons as a group. Rather they offered services to *multiply* handicapped deaf persons (i.e., there was little homogeniety among the students/clients served except for the common disability of deafness).

PERCEIVED SERVICES FOR HIDD PERSONS IN ARIZONA

The second activity, a needs assessment conference (Stewart, 1977) was held in Tempe, Arizona, in January, 1977. At that time, 90 persons from schools and agencies located throughout the State of Arizona convened at Arizona State University "for the purpose of sharing ideas and identifying priority needs" of HIDD persons. The participants were teachers (17), administrators (39), speech/language pathologists (10), audiologists (7), counselors (6), parents (3) physicians (1), and others (15). These participants shared information regarding existing as well as needed services, and then identified those services that required further development. Identified needs were as follows:

A. *Population Identification.* The following priorities emerged in the area of population identification.

1. *Coordination of Efforts.* It was felt that effective population identification efforts are directly contingent upon coordinated efforts on the part of agencies, schools, and organizations that serve HIDD persons. Accordingly coordination of efforts emerged as the top priority.

2. *Public Awareness.* Greater public awareness of HIDD persons and their assets and needs was considered next in priority since it was felt that population identification is dependent in large part upon knowledge of identifying characteristics.

3. *Professional Training, Technical Assistance.* Since population identification is dependent upon an awareness of the characteristics of HIDD persons, such identification can be greatly facilitated through the provision of training and technical assistance to professionals who work with special populations.

4. *Improved Techniques of Identification.* Professionals perceive themselves as needing help in improving their techniques for identifying HIDD persons. This is reflected in the priority ratings.

B. *Programs.* Respondents noted the following priority needs in the area of organized program efforts for HIDD persons.

1. *Adult Service Programs.* Adult service programs were seen as the top priority in this area. Such services included, but were not limited to, community living arrangements and sheltered workshops. Meeting this need would give a major boost to deinstitutionalization efforts.

2. *Coordination of Services.* Again, a major need exists for coordinating community opportunities for HIDD persons. Such coordination would facilitate optimum integration of efforts, funding, and manpower.

3. *Diagnostic Centers.* Diagnostic centers geared toward early intervention were given high priority in the area of program development. Such centers would foster an early attack on conditions that eventually lead to severe handicaps.

C. *Services.* In the area of development of specific kinds of services within overall programs of services, the following priorities emerged.

1. *Comprehensive Medical Assessment.* There is a pressing need for comprehensive service efforts in the area of medical assessment. Special areas of concern encompass audiological assessment, otological assessment, and psychological diagnosis.

2. *Parent Education.* Parent education, guidance, and counseling were rated of second highest priority in the area of service needs.

3. *Community Living.* Provisions for community living training and on-going residence were listed in third order in priority rankings.

D. *Prevention Efforts.* Four priority needs arose in the area of efforts to prevent HIDD conditions.

1. *Parent Training.* Training for parents is needed in the area of signs and symptoms of hearing impairments, and developmental disabilities, and in prenatal and nutritional care and prevention of health disorders.

2. *Professional Training.* Next in order of priority was professional training in the etiology and prevention of hearing impairment and development disabilities. Workshops and dissemination of current research literature to resource agencies are potential mediums for such training.

3. *New Neonatal Screening Techniques.* New neonatal screening techniques are needed to detect infants with high risk of hearing impairment and developmental disabilities.

4. *Immunization Programs.* There is a need for improved immunization programs and public awareness efforts about diseases known to cause hearing impairments and/or developmental disabilities. Maternal rubella, for instance,

is a major cause of multiple disabilities associated with HIDD conditions. Immunization would largely prevent this disease.

E. *Coordination of Efforts.* Five priority needs were identified in the area of coordination of efforts.

1. *Public Awareness.* Increased public awareness of HIDD persons was seen as the top priority in achieving effective coordination of efforts. The reason here is that public awareness frequently generates program development efforts.

2. *Agency Communication.* Next in order of priority was the need for greater sharing of information among agencies and other groups that serve HIDD persons. This need was seen as a difficult one to meet because of the mass of information faced by most agency planners. One possible solution will be to develop improved techniques for interagency communication.

3. *Program Funding.* The third priority was that of coordinating applications for funding of programs for HIDD persons. The many developing efforts to serve HIDD persons require effective coordination if efficient funding patterns are to be realized. Otherwise, costly service programs would develop and might jeopardize overall efforts.

4. *Comprehensive Planning.* Next in order of priority was the need for comprehensive, coordinated planning of services for HIDD persons. Such planning should anticipate and include provisions for future service needs.

5. *Indian Planning Council.* The final priority need was for inclusion of the Arizona Indian Planning Council in the network of services for HIDD persons. This Council could help to give important direction to such services as they relate to serving Indian groups.

F. *Professional Training.* In the area of professional training, priority was placed upon providing opportunities for degree and in-service training as follows:

1. *Long Term (Degree) Training.* Multidisciplinary training opportunities that include specialization in, or orientation to, HIDD persons, were needed for the following:

Discipline	Level
a. Counseling with parents of HIDD persons and with HIDD clients	M.A.
b. Teachers with HIDD clients	M.A.
c. Social Work with HIDD clients	M.A.

d. Interpreter training — Undergraduate

e. Psychological services with HIDD persons — Ph.D.

2. *Short Term (Workshops, Seminars).* The following topical areas were recommended as priority workshop topics:

a. Psychosocial aspects of HIDD persons.

b. Teacher orientation to HIDD persons' needs and curricula content

c. Orientation to HIDD persons for medical personnel

d. Orientation to HIDD persons for interpreters

e. Orientation to HIDD persons for speech and hearing specialists

G. *Research.* In the area of research, the following priorities emerged.

1. Evaluation of educational methodologies and techniques with HIDD persons of all ages and functional levels.

2. Evaluation of teacher selection, skills needed in personnel selection, and evaluation of professional training models.

3. Evaluation and development of curricula methodologies with HIDD persons, especially those developed for "single disability" groups (e.g., the deaf, the mentally retarded).

4. Research in the development of evaluation tools for HIDD groups, expansion of functional classification instruments, and effects of improved observation skills on client training.

H. *Instructional Technology.* Instructional technology for programs serving HIDD persons remained an area in need of major innovations. The following priorities were identified by Workshop participants.

1. *Curriculum Materials.* Top priority in the area of instructional technology was identified as the need for curriculum materials, particularly for the development of skills in language, reading, activities of daily living, and survival skills in community living.

2. *Central Clearinghouse.* Next on the list of priorities was the need for a central clearinghouse with a lending library for instructional equipment and materials that are currently too costly for individual program acquisition.

3. *Continuing Education.* A third identified priority need was for continuing education opportunities for teachers who need help with instructional technology for HIDD students. This need seemed to be basic to future program upgrading.

4. *Funding.* An important priority need was for funds for the development of instructional materials. While such funds might be available "somewhere," there was a need for a resource where teachers and developers may turn for guidance regarding funds.

5. *Vocational and Career Development.* A fifth priority need identified was that of instructional technology for utilization in vocational and career development efforts involving HIDD students and clients.

Health. Health needs represented an important but frequently overlooked area of concern in the consideration of educational needs of HIDD children and youths. The following five priority needs were identified by Workshop participants.

1. *Preventive Medicine.* The highest priority was that of preventive medicine, including early diagnosis, genetic counseling, and PKU testing of infants.

2. *Coordination of Rural Services.* Second priority was given to better coordination of comprehensive rural health services. Services to rural residents are too often sporadic and lack comprehensiveness of coverage. A coordinated, comprehensive approach would do much to improve preventive as well as developmental conditions for HIDD persons.

3. *Public and Parent Education.* Many of the conditions causing HIDD disabilities are created by poor health care practices by parents and others involved in the child's life. Improved health practices with children would result from parent education and public information.

4. *New Technology.* Research and training in the area of new technology in health care as such relates to HIDD persons and the prevention of HIDD disabilities was rated fourth in priority.

5. *Current Understanding.* Communicating with the HIDD client was rated a priority need. Health professionals would foster improved health care for HIDD persons if the were to develop more effective communication skills with HIDD patients.

J. *Facilities.* Facilities, or buildings and physical plants, for utilization by HIDD individuals in meeting their needs were considered in this topical area. In general, Workshop participants felt that physical plants were available for most purposes but there was a need for reorganization and use of these existing facilities through comprehensive planning. Top priority for such reuse was as follows:

1. *Workshops.* Top priority for facilities was given to the establishment of regional (i.e., Southern Arizona, Central Arizona, Northern Arizona) prevocational training and sheltered employment workshops for HIDD persons.

2. *Community residence facilities.* Sharing top priority with workshops was regional community residence facilities for HIDD persons. It was felt that until such facilities are available, deinstitutionalization of HIDD persons will have very little prospect of success.

3. *New Employment Opportunities.* A third priority need identified was that of advocacy for expansion of employment opportunities for HIDD persons. It was felt that current opportunities are restricted unnecessarily by a combination of factors including inadequate training opportunities, low aspirations for HIDD persons on the part of service workers, and devaluing, or low expectations, of HIDD persons on the part of employers.

4. *Diagnostic and Planning Centers.* Fourth priority was given to the development of multidisciplinary diagnostic and service planning centers for HIDD persons, such centers to include provisions for rural services, support services for HIDD persons with visual impairments and in-service training for allied personnel.

5. *Regional Education Programs.* The fifth and final identified priority need was for regional education program facilities beginning with preschool programs for HIDD infants and their parents. Such programs can be expected to have major positive impact in the development of higher functional skills in HIDD persons.

Top Priority Needs. Priority needs within each topical area were identified. Further, the top overall needs in serving HIDD persons in Arizona, as judged by workshop participants, were as follows:

Priority I: *There is a major need for greater coordination of efforts on the part of all agencies and advocacy groups serving HIDD persons.* Improved coordination would result in greater program effectiveness, better cost effectiveness, minimize duplication of efforts, improve interagency communication, and precision in filling service gaps.

Priority II: *There is a pressing need for immediate in-service training opportunities for agency professional staff who serve HIDD persons.* Continuing education opportunities are urgently needed in the major population centers as well as in selected rural areas. Degree training is needed in anticipation of long term program needs.

Priority III: *Multidisciplinary planning for the continuum of service needs of HIDD persons at the present time and for the future is desperately needed.* A comprehensive services delivery system, covering prenatal needs through services for elderly HIDD persons, should be planned and implemented.

Priority IV: *Regional comprehensive diagnostic, education, training, vocational and residence centers are needed urgently,* and should be planned as a part of Priority III activities.

These priorities were identified according to opinions expressed by Workshops participant *groups,* or, in other words, were arrived at concensually. As such, they reflect the views arrived at by *majority vote* of the persons present at the Workshop. However, a crucial point became clear through an analysis of the *individual* views of participants.

Specifically, it was determined that the administrators present at the Workshop viewed HIDD services quite differently from front line service workers. Briefly, the administrators perceived services for HIDD persons as both currently available and as accessible, whereas the front line workers viewed such services as not available or inaccessible.

This view was further supported by the previously described survey of state and local agency administrators, which resulted in the listing of 114 organizations (schools, agencies) in the state which purportedly served HIDD persons. The following discussion highlights these conflicting administrator vs. service worker viewpoints.

The findings of the needs assessment workshop and survey of resources presented a baseline for evaluating the recommendations of recent publications (cf., Healey, 1975; *Task Force Report,* 1973) and gaining a firmer grasp of the scene in Arizona in serving hearing impaired developmentally disabled persons. The avenue of approach that was used permitted a more comprehensive perspective than has usually been the case. Findings from the literature, recommendations made by local professionals, paraprofessionals, and parents, and data supplied by school and agency heads was synthesized into tentative conclusions that in turn were used to bring firmer focus to the directions that were taken in advancing efforts to serve hearing impaired developmentally disabled persons in Arizona and, later, the rest of the country.

Emerging Consensus and Conflict: As indicated earlier, Healey (1975) listed three major weaknesses in our country's current efforts to serve hearing impaired mentally retarded persons. These were (1) lack of information, (2) lack of coordinated planning, management, and program evaluation, and (3) lack of sufficient resources.

The findings in Arizona, at first glance, both supported and refuted these findings. The Model Demonstration Program's survey of agencies and schools

indicated that there were numerous resources, personnel, and services for HIDD persons in Arizona. Whether these were sufficient could not be ascertained at the time from available data. However, opinions of knowledgeable professionals and parents, gained form the Needs Assessment Workshop, concurred with Healey's (1975) findings and cast a shadow of suspicion over the validity of the MDP's survey data. Point by point, the Needs Assessment Workshop findings were contrasted with survey findings and implications drawn therefrom.

Point 1 - Coordination

Needs Assessment Finding: "There is a major need for greater coordination of efforts on the part of all agencies and advocacy groups serving HIDD persons."

Survey Finding: The survey of agency heads did not specifically address the coordination function. However, the data casually imply some limitation of enthusiasm for efforts on behalf of HIDD persons. Specifically, the MDP offered extensive resources for HIDD programs, yet only 31 out of 88 schools purportedly serving HIDD pupils expressed interest in utilizing MDP staff resources.

Implication: The coordination aspects of services for HIDD persons in Arizona should be studied in an attempt to determine (1) whether coordination is effectively occurring and, if not, (2) why effective coordination is not being achieved, and (3) given Arizona's resources and limitations, what can be done to achieve effective coordination.

The Model Demonstration Program's *ad hoc* committee on services coordination had recommended that the MDP undertake a major study of coordination among agencies and schools that serve, or could serve, HIDD persons. The committee felt so strongly about this that it recommended that MDP contact the Governor's Office to solicit top level department support for, and cooperation in, this study. [However, because of changes in governmental leadership (Arizona had three governors in the span of two years!) this effort was not completed.]

Point 2 - Professional Training

Needs Assessment Finding: "There is a pressing need for immediate inservice training (and degree) opportunities for agency professional staff who serve HIDD persons."

Survey Finding: Among the agencies and schools reportedly serving HIDD persons, "a total of 1,387 fulltime and part time professional and paraprofessional persons were reported to be available to serve the HIDD population in Arizona as of April, 1977."

Implication: The MDP survey results had to be interpreted in the light of the question of adequacy of services. Without doubt, there *were* numerous workers in Arizona who served HIDD persons in some way. *The issue was boiled down to how*

effectively these workers served HIDD persons. Participants in the Needs Assessment Workshop obviously felt that specialized skills in working with HIDD persons are required and that there were few persons in Arizona with such skills. In the survey, perhaps agency and school administrators were simply considering the number of workers who did in fact relate to HIDD persons *in some way or another,* without regard to the quality or adequacy of coverage of needs. [We suspected this was the case, but we could not be sure at the time.]

Point 3 - Comprehensive Planning

Needs Assessment Finding: "Multidisciplinary planning for the continuum of service needs of HIDD persons at the present time and for the future is desparately needed."

Survey Finding: The survey of schools and agencies indicated the existence of many programs, *or perceived programs,* for HIDD persons. Yet, a report from the Arizona Diagnostic, Treatment and Education Center – a specialized educational facility for multiply handicapped children – indicated that more than 100 multipy handicapped children, a large number of whom were HIDD, were awaiting services from ADTEC because the facility was filled to capacity. If there were so many programs for HIDD children, why were so many children on ADTEC's waiting list?

Implications: The MDP drew the conclusion from the available data that while there were schools and agencies serving, *in some way,* HIDD children and adults, for the most part these services were minimal or focused on only a part of the HIDD individual's total needs. [Again, however, we could not then be sure of this hypothesis.] We speculated that a comprehensive analysis of programs for handicapped children, particularly the HIDD population, would show that HIDD services were *overestimated* for the most part and there was actually minimal effort at long range planning and program development. MDP staff contacts had in fact elicited concern from agency front line workers over the then-current limitation in planning efforts.

Point 4 - Comprehensive Centers

Needs Assessment Finding: "Regional comprehensive diagnostic, education, training, vocational and residence centers are needed urgently."

Survey Findings: Survey findings indicated that there was a reportedly large number of programs (114) or HIDD persons providing a comprehensive range of services.

Implications: MDP staff experience suggested that there were few facilities within Arizona that provided a quality level of substantial services for HIDD persons. True, there were many programs offering some type of meaningful service to this group, but unfortunately lack of staff and funds preclude concentrated program services covering the broad needs of HIDD persons. The mix, the

comprehensiveness, the depth needed, just cannot be made available in any facility other than one having large numbers of HIDD children *and* staff experienced with HIDD persons.

STATE DEPARTMENT OF EDUCATION PERCEPTIONS

The third activity consisted of a survey of state departments of education (Perine, 1977). In this study, a letter was sent to every state level department of education asking the following questions:

a. What are your presently functioning HIDD programs (residential, day, within the regular school program)?

b. What are your proposed HIDD programs?

c. What are the current state guidelines for serving HIDD persons?

Only twenty states replied to the survey, resulting in a 40% response rate. The results of the survey are summarized below:

> Apparently, a number of the states that offer educational programs which have the potential to serve the HIDD population identify only services for the hearing impaired and assume that "other" students are served within those programs. This is supported by the fact that 80% of these states offered the name of the State School for the Deaf as the primary source of service for the HIDD population. In fact, a majority of the respondents felt that the developmentally disabled students were being served within various deaf education programs, regardless of location. Therefore, it seems as if the hearing impairment is the determinant of services for this group.
>
> The author goes on to state:
>
> On the other hand, 7 of the 20 responding departments included these services under programs for the "Multiply Handicapped." In several cases, the HIDD population was purported to be served within existing deaf-blind programs. This would indicate that the hearing impairment is equal in importance to "other" disabilities. Unfortunately, many of these programs were described in non-specific terms which only implied potential services available for HIDD population. Only 3 of the respondents stated unequivocally that they had public school HIDD classes, and this totalled 6 classrooms.
>
> The nature of the information received ranged from a thorough explanation of the statewide array of educational services such as those available in Indiana, to a listing of school districts and/or directors of special education programs (several respondents sent material of this type). The emphasis in the overwhelming majority of the letters, lists, and booklets, however, was on programs for the hearing impaired with only a peripheral reference to the developmental disabilities.

What does all this mean? How does this data speak to the issue of education for individuals who are hearing impaired/developmentally disabled? In general, the information points to the lack of programming for this population as well as an overall misunderstanding of the service needs of the HIDD group. Without fail, those respondents who were not sure of what services were offered, or who offered them, referred our investigator to the state school for the deaf. The assumption was that there must be something at the school for the deaf since that is the obvious place to serve the hearing impaired/other involved. In fact, the preponderance of information received in reference to exisiting services for this population was in the area of programs for the deaf. Therefore, one should assume that a survey of schools for the deaf, or specialized programs for the hearing impaired should be carried out. A follow-up study is planned to verify this assumption. (Perine, 1977, p. 2-3).

The conclusion of this study stated:

Unfortunately, there is one major conclusion that can be reached given the number and nature of the responses to the survey. There are few viable educational programs currently operating through the resources of the state departments of education throughout the United States, and the lack of a recognition of hearing impaired/ developmentally disabled as a population of significant size.

It is critical that each of these issues be addressed separately in order to develop both programs and a foundation for legislation that will enhance the success potential for a truly educationally deprived population within the United States. (Perine, 1977, p. 3)

The Perine (1977) study supports the hypothesis that confusion and lack of information among agencies and administrators regarding HIDD persons are major reasons for the absence of program growth for these children and adults.

As we shall see in the next section (below), further support for such a hypothesis is generated by this same lack of information among administrators of schools for the deaf.

Perceptions of Administrators of Schools for the Deaf

The fourth activity consisted of a survey of 54 schools for the deaf listed in 1977 "Directory of Services" of the *American Annals of the Deaf* (April, 1977). The survey (Milone, Perine & Stewart, 1978) was designed to solicit information from superintendents of these schools relative to 12 questions concerning educational services for HIDD persons. These questions, and responses of the 39 superintendents, who responded, are presented below:

1. Do you feel that your school is the principal focus of educational services to hearing impaired children in your state?

   28 Yes
   7 No
   4 Undecided

   Thus, 70% of the 39 superintendents felt that their school served as the principal focus of educational services for the deaf (and, presumably, for HIDD persons) in their state.

2. Do you provide special programming for your hearing impaired students with additional handicaps?

   32 Yes
   7 No

   These results indicate that 82% of the superintendents reported that their school provided special programming for its hearing impaired students having additional handicaps.

3. If you answered yes to question 2, please indicate which of the following additional disabilities are targeted for programming in your school.

   Among the 32 schools offering special programming, the following additional disabilities were targeted for programming by the indicated number of schools:

   24 Mental Retardation
   7 Autism
   8 Epilepsy
   15 Cerebral Palsy
   17 Visual Impairment
   15 Orthopedic Impairment/Other Health Handicap
   24 Learning Disabilities
   22 Emotional Disturbance/Behavior Disorder

4. Developmental disabilities include mental retardation, autism, epilepsy, and cerebral palsy. Do you at the current time maintain a special program for hearing impaired students with developmental disabilities?

   18 Yes
   14 No
   7 Not sure

   These results are in conflict with responses to Question No. 3, and consequently suggest inconsistency in responses. However, the fact that less than half of these schools offer a special program for HIDD persons suggests that either the majority of schools for the deaf do not offer special

programming for HIDD students *or* the majority do not (a) serve HIDD persons or (b) do not know some of their students are HIDD.

5. Does your school plan to develop and/or maintain, within the near future, a special program for hearing impaired students with developmental disabilities?

   24 Yes
   4 No
   7 Not sure

   These responses indicate that the future may see a growth of special services for HIDD children at several schools for the deaf, but also that almost one-third of the responding superintendents will not or may not pursue such special programming.

6. If you do plan to have a special program for hearing impaired developmentally disabled students, which of the following components will constitute the program:

   25 Psychoeducational diagnosis
   26 Special educational placement
   26 Vocational training
   13 Mainstreaming with support
   8 Other

   Eight residential schools reported that they were offering or planning to offer certain services other than those listed above. These various services included:

   staff training
   pre-vocational training
   occupational and physical therapy
   residential
   career education
   special medical team support services
   special unit to prepare HIDD students for entry into regular classroom with other hearing impaired students.

7. Do you have a formal diagnostic procedure to establish the presence of any of the developmental disabilities in conjunction with a hearing impairment.

   21 Yes
   17 No

   One of the most important aspects of educating any student is a diagnostic procedure that can serve to identify the strengths and weaknesses upon

which the educational plan for a student can be built. Yet, more than 40% of the schools surveyed stated that they had no formal diagnostic procedure to establish the presence of a developmental disability. This finding suggests that a great many HIDD students are either being diagnosed informally, or are not being diagnosed at all.

8. What type of relationship do you have with public school day programs for hearing impaired students in your state:

   12 A formal relationship, described in the policy and procedure documents of your school.
   15 An informal relationship maintained by individual staff member.
    4 No relationship at all
    8 Other

   The respondents who indicated that they maintained a relationship of a type other than formal or informal offered the following alternatives:

   - A relationship through the Department of Public Instruction
   - Quarterly meetings with personnel from the Exceptional Child Section of the State Department of Education
   - Interaction of Superintendents
   - Coordinating and resource entity for other programs serving hearing impaired students
   - Offering vocational training for hearing impaired students in day schools

9. If you maintain a formal or informal relationship with public school day program, which of the following activities constitute the relationship:

   19 Diagnostic services
   22 Educational consultation
   21 Administrative consultation
   17 In service training
   10 Materials development
   14 Outreach/child find
    4 Counseling
   19 Audiology services
    8 Other

   The following activities were among those offered by those schools that responded "other" to this item:

   - Consulting on placement
   - Information sharing
   - Student exchange program
   - Consortium type activities
   - Transition classroom
   - Captioned films

10. What type of relationship do you maintain with other schools and programs serving children with a handicap other than deafness?

6 A formal relationship, described in the policy and procedure documents of your shcool.
28 An informal relationship maintained by individual staff members.
4 No relationship at all
1 Other

11. If you maintain a formal or informal relationship with other schools and programs serving children with a handicap other than deafness, which of the following activities constitute the relationship:

12 Diagnostic services
17 Educational consultation
11 Administrative consultation
9 In service training
4 Materials development
12 Outreach/child find
7 Counseling
13 Audiologic services

Under the category of other were:

- Mutual accountability to the same source
- Placement
- Coordination of policies, procedures, and implementation
- Information sharing

12. What percentage of your teachers hold multiple certificates?

6 More than 50%
7 Between 25% and 50%
9 Between 10% and 25%
11 Less than 10%
2 None at all
4 Can not estimate

This item was worded in such a way that it was not clear to some of the respondents what question was really being asked. Because the item followed other items relating to general special education, it was assumed that respondents would indicate what percentage of their teachers possessed certification that would allow them to teach children with disabilities other than deafness. Some respondents, however, interpreted the item to mean certification in content areas. Interpreting the results of this item in light of this potential misinterpretation would be inappropriate.

PART III: Needs Assesment Results and Project Focus

The results of the needs assessments that have been described assisted the project in arriving at several conclusions that were to pave the way for focusing staff efforts in the most product directions. These conclusions were:

1. Little was actually known about the HIDD population even by personnel in the schools and agencies traditionally charged with serving the hearing impaired population and those serving the developmentally disabled population.

2. Program administrators and planners tended to overlook the special needs of HIDD persons, and thus perceived their agencies as providing adequate services to these persons even when such was not the case, judging from opinions of special front line service workers.

3. Schools for the deaf were perceived as THE resource for HIDD persons, even when their administrators indicated independently, that they serve *only* (a) children of certain ages, (b) children with certain levels of hearing loss, and (c) children with certain degrees of severity of impairment in functioning.

4. There were *many* schools and agencies potentially capable of serving HIDD persons, but too many of them lacked properly prepared staff for dealing with the communication and other special needs of HIDD children and adults. Hence, technical assistance and professional training emerged as prime needs in preparing personnel for serving HIDD persons.

5. Major reasons accounting for the minimal efforts to develop services for HIDD persons were:

   a. Widespread lack of awareness that schools for the deaf offer only limited services to this group;

   b. A general lack of awareness that public schools and general agencies are *not* doing an adequate job with HIDD persons;

   c. HIDD persons are a minority group in every single agency or school that attempts to serve them. Each school/agency almost always has *one primary focus* (e.g., deaf, mentally retarded, or other), and its major services are centered around this focus. Other disabilities are usually secondary concerns. In this climate, multiply disabled persons are usually not seen as a priority group; they are usually not given special attention and/or special funding. HIDD persons are "round pegs forced into square holes." Even when the multiply disabled are given the benefit of special attention, such as being served in a special "department" or program, the heterogeneity of the student population is such that effective instruction is at best quite difficult. An example is the "special" unit serving such widely diverse groups as the deaf-blind, blind-mentally retarded, deaf-mentally retarded, deaf-mentally retarded-cerebral-palsied, and deaf-emotionally disturbed.

6. Advocacy for HIDD persons was minimal and unorganized, hence few effective efforts were made to bring their needs to the attention of planners and administrators. No known attempts were made to enact enabling legislation designed to compensate for shortcomings in school and agency planning for HIDD persons.

Accordingly, the project staff was led to respond to the findings of its needs assessment in the following manner:

1. Rather than attempt to operate one single "center" for HIDD persons, the project would cooperate with existing schools and agencies and attempt to work with them in strengthening and upgrading their services for the benefit of HIDD persons.

2. Training and Technical Assistance (T/TA) services would be a major activity in effecting Number 1 above.

3. Extensive efforts would be undertaken to identify or develop appropriate instructional and public/professional education materials that could be used to increase awareness levels concerning HIDD persons, their needs, and how these needs could be met. These materials could then be disseminated to appropriate audiences through the project.

4. Demonstration services would be carried out as necessary and feasible to develop innovative services for HIDD persons in such areas as audiological screening and assessment, counseling, community residential living [group homes, independent living training centers, etc.], diagnosis, and other areas as identified through project staff experiences. The process of identifying service gaps would have implications not only for the project but also for the schools and agencies that perceived themselves as already meeting the needs of HIDD persons.

SUMMARY

This chapter has attempted to describe, and in some cases explain, the events that transpired in project attempts to initiate its proposed activities. The problem of translating theoretical service concepts into operational reality was recognized as a major one with the Model Demonstration Program. With so much already done in prescribing program elements for the HIMR (see Healey, 1975), and with strong Federal legislation already existing that could fund local programs for HIDD persons, the fact that the nation was yet doing very little for this population alerted the project to the fact that *actually* developing HIDD services would not be a simple matter. As it turned out, in most cases service providers in schools and agencies did not actively acknowledge that there were specific problems in serving HIDD persons. Even those who were aware of the problems tended to assume that the state school for the deaf was taking care of them. Hence, not only did the project have to develop "models (prototypes) of services"; it also had to *persuade*

others that (a) HIDD persons have special needs and require special services, and (b) that the state school for the deaf, rather than being the primary resource for HIDD persons, is only one resource out of many that are needed.

These considerations led the project staff to establish its priorities in implementing the Model Demonstration Program, and, moreover, these priorities changed over time in response to the needs that became apparent as a result of experience with particular schools, agencies, and governmental officials. Chapter 6 presents the program of activities of the project in a detailed manner, and describes the results.

Fundamental to the work of the project was a proper understanding of the HIDD population. During the time preceding the inception of the Model Demonstration Program, professional attention to the broad classification, "hearing impaired developmentally disabled," had been minimal. Thus, it was decided by the project that basic population descriptive and prevalence of information was necessary for guiding its service, research, and training efforts. The next chapter presents this information.

CHAPTER 5

HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS: DESCRIPTIVE POPULATION INFORMATION

In Chapter 1, the definition of "developmental disabilities" according to P.L.-103 (The Disabled Assistance and Bill of Rights Act, 89 Stat. 486, 1975) was presented. This is the definition used by the Model Demonstration Program throughout its service, research and training activities, and this will be reflected in this chapter as well as the chapters to follow. However, the reader should bear in mind that a new, broader definition has been developed and is currently (1979) being used by agencies and schools serving the developmentally disabled. The new definition will be presented at the end of this chapter. For this report, however, the definition from P.L. 94-103 is used since it was in effect during the major work of the project.

INTRODUCTION

At the time the project was funded, there had been no substantial efforts made to define the HIDD population or to conduct related prevalence studies. Without such information, the Model Demonstration Program could not effectively approach schools and agencies from a strong position of advocacy, nor could the project systematically plan its own programmatic activities. Constantly recurring questions were "Who ARE the hearing impaired, developmentally disabled? What are their problems? What are their needs? How many are there?".

In a determined effort to answer these basic questions, the project staff designed a series of activities that were carried out during the first two years. These activities consisted of:

a. A review of the professional literature
b. Use of extrapolations from widely accepted demographic studies and prevalence estimates
c. Compilation of demographic data from:
   (1) The Individualized Data Base, UCLA/Neuropsychiatric Institute
   (2) Schools and Agencies in Arizona
   (3) Project referrals

The resulting information is reported in this chapter in three sections entitled "Specific Characteristics," "I.D.B. Findings," and "Project Findings." Together,

these three sections provide a comprehensive, detailed "State of the Art" description of the HIDD population.

SPECIFIC CHARACTERISTICS

Developmental Disabilities

The characteristics of developmentally disabled persons are well defined in the HEW publication, *What are Developmental Disabilities?* (1976), as reported by T. Cerva in an unpublished paper (1977). The following excerpts are quoted from that source.

1. Autism

A. *Description.* Autism refers to severe disorders of communication and behavior which begin in early childhood. The word is from the Greek autos, which means "self," reflecting the stage children go through when they are withdrawn into themselves and do not show interest in others. Autistic children include those afflicted with infantile autism (Kanner's syndrome), childhood psychosis, childhood schizophrenia, or other conditions characterized by severe deficits in language (such as profound aphasia), behavior, and by the inability to relate to others.

B. *Causes.* The causes of primary childhood autism are not known. Autism is found throughout the world, in every social class, with a uniform clinical picture. Many autistic children have abnormal or borderline brain wave patterns, and a small proportion develop seizures. Evidence suggests that autism is like some of the inborn disorders of metabolism.

C. *Effects.* There is a lack of contact with reality. The universal symptom is the child's inability to relate to other persons in a normal way. This becomes more apparent as the child grows older. "Autistic aloneness" is characterized by staring at space, nonresponses to sounds, and a total lack of interest in other persons. Other common characteristics include failure to use speech effectively, rocking or other repetitive behavior, tantrums, difficulties in toilet training, problems in feeding, and absence of social awareness. Autistic children can show normal skill in some isolated areas of functioning, such as mathematics and music performance.

2. *Cerebral Palsy*

A. *Description:* 'Cerebral' refers to brain, 'palsy' to lack of control over muscles. It is not a single disorder but a group of dysfunctions having a variety of symptoms. All are brain centered and all affect muscular control as well as sensory functions. There are three main

types: The spastic persons move stiffly and with difficulty. The athetoid has involuntary and uncontrolled movements. The ataxic has a disturbed sense of balance and depth perception.

B. *Causes:* Poor maternal nutrition and health before and during pregnancy can affect the brain development of the baby. Any damage to brain tissue can cause cerebral palsy, whether the result of defective development, disease or an injury occurring any time in life. A chief cause is insufficient amount of oxygen reaching the fetal or newborn brain. Other causes might be premature birth, Rh or A-B-O blood type incompatibility between parents, or infection of the mother with German measles or other virus diseases in early pregnancy, and viruses attacking the newborn's central nervous system.

C. *Effects:* There is difficulty in muscular control and coordination. Sometimes cerebral palsy shows itself only by slight awkwardness of gait or hand movement. More often there are other complications, such as seizures; the inability to see, hear, speak, or learn as other people do; or psychological and behavioral problems. Cerebral palsy is not always associated with mental retardation. Any combination of physical and mental states is possible.

3. *Epilepsy*

a. *Description.* The term epilepsy (or 'the epilepsies') applies to a number of disorders of the nervous system, centered in the brain. While the term comes from the Greek word meaning 'to be seized,' epilepsy is a symptom of a disorder of the central nervous system. It is characterized by sudden seizures–muscle convulsions and a partial or total loss of consciousness–due to abnormal electrical discharges of brain cells.

b. *Causes.* There is no precise answer as to why brain cells discharge abnormally. Epilepsy can result from defects in the brain; brain injury before, during or after birth; head wounds; chemical imbalance; poor nutrition; childhood fevers; some infectious diseases; brain tumors; and some poisons.

c. *Effects:* Seizures of one kind or another are the primary characteristic of all forms of epilepsy. The three major types are: Grand mal seizures last a minute or more and can occur one or more times daily, weekly, monthly, or annually. The victim loses consciousness and has convulsions. Afterward he is confused or drowsy and might sleep for several hours. Petit mal, most common in children, lasts from 5 to 20 seconds and can occur many times an hour. It can be accompanied by staring or twitching of the eyelids and momentary lapse of consciousness. The patient is seldom aware he has had a seizure. Psychomotor seizures can occur at any age. They have the most complex pattern of behavior, including activities such as chewing and lip-smacking, staring and confusion, abdominal pains and headaches,

changes in color perception, spots before eyes, ringing ears, dizziness, fear, anger, and, following the seizure, sleep. The seizure might last from a minute to several hours. After the attack, the person is unable to remember what happened. It is important to know that epilepsy usually does not affect a person's intelligence.

4. *Mental Retardation*

A. *Description:* Persons who are mentally retarded are limited in their ability to learn and are generally socially immature. Some are further handicapped by emotional and physical disabilities. There are significant sub-average intellectual functioning and defects in adaptive behavior. Mental retardation is a condition, not a disease, manifested during the developmental period.

B. *Causes:* About 80% of retardation has socio-environmental causes, not biomedical causes. Among the latter causes of mental retardation are: genetic and chemical abnormalities, poor maternal nutrition and malnutrition in infancy, damage to the central nervous system, toxic agents (such as lead), viruses, or brain injury early in life. Premature infants are especially vulnerable, as are children born to women over 35.

C. *Effects:* Retardation has been divided into four levels: mild, moderate, severe, and profound. Mildly retarded persons differ from nonretarded people in rate and degree of intellectual functioning and are usually not identified as retarded until they enter school. As adults they are often absorbed into the competitive labor market. Moderately retarded persons are usually identified before they reach school age. They, too, may become productive members of the community through appropriate education. Severely and profoundly retarded persons can learn to care for their basic needs and can adapt to normal patterns of life.

Mentally retarded persons are found among every race, religion, and nationality, as well as every educational, social, and economic background. However, there is a greater likelihood of socio-economically caused mental retardation in lower socio-economic classes.

Hearing Impairment

Although Schein and Delk (1971) used a simple but nevertheless effective, for their purposes, definition for hearing impairment (i.e. "all signficant deviations from normal, including deafness"), they recognize, as do other works in the area of deafness, that no single definition can meet the needs of the varied disciplines that work with hearing handicapped persons. The definition offered by Healey (1975) appears to be a workable one, and is offered below:

a. Description: Hearing impairment is a generic term indicating any loss of hearing from mild to profound as indicated otologically, audiometrically, and functionally. The term generally includes the subclassifications of deaf and hard of hearing.

Four basic factors are normally considered when defining hearing impairment. These are: site of lesion (the type of hearing loss: sensorineural, conductive, or central) etiology (cause of hearing loss: heredity, disease, trauma); age at onset (effect on language and speech development); and, degree of hearing impairment (audiometric and behavioral) (Healey, 1975, p. 7).

B. Causes: The causes of hearing impairment are many and varied, as is the case with the developmental disabilities. Etiologic factors include heredity; Rh factor incompatibility in the parents; pregnancy complications; infection of the mother with German measles or other virus diseases in early pregnancy; prematurity; otitis media, meningitis, mumps, measles, and other diseases; high fever; infection; and trauma after birth.

C. *Effects:* As suggested in A above, the effects of hearing loss are mediated by etiology, site of lesion, age at onset, and degree of hearing impairment. Additionally, the extent and kind of remedial action taken (e.g., medical treatment, auditory amplification, surgery, communication skills training, special education) immediately following the onset of hearing loss have a profound impact on the outcomes of such loss. Generally, the earlier the age at onset and the greater the degree of loss, the more serious will be the effects in such areas as language, speech, social development, and general knowledge.

Hearing Impairment and Developmental Disabilities

The combined disabilities of hearing impairment and one or more of the developmental disabilities constitute a set of conditions that has received relatively little attention in the professional literature up to the present time. However, by combining and modifying the preceding definitions and using these as a base, we now offer the following definition:

A. *Description:* The hearing-impaired/developmentally disabled are those persons who have a hearing impairment in combination with a disability which had its onset prior to the age of 18 years and is attributable to mental retardation, cerebral palsy, epilepsy, autism, or any other condition of a person found to be closely related to mental retardation and which is a substantial handicap that can be expected to continue indefinitely.

B. *Causes:* The causes of hearing impairment and developmental disabilities are usually similar to those listed for the preceding single category developmental disabilities and for hearing loss.

C. *Effects:* The effects of this multiple disability, again, are comparable to those previously listed for single category disabilities. However, rather than resulting in an additive effect (e.g., the handicaps of hearing loss plus the handicaps of a developmental disability), the effect is one of multiplication (hearing loss plus developmental disability plus the combination). An example would be a

hearing-impaired, mentally retarded person who must deal not only with the handicaps of a loss of hearing and the handicaps of mental retardation, but also the reciprocating flow of limitations in both areas. Such a person would have a more difficult time learning because of hearing loss, and this further diminishment of *use* of auditory input would increase retardation, and the increased retardation would further impair one's ability to use residual hearing, and so on in a devastating downward spiral.

Again, the impact of hearing impairment among the developmentally disabled is determined by the etiology, age at onset, site of lesion, degree of hearing impairment, extent and nature of early intervention strategies, and accompanying disabilities.

Population Prevalence Estimates

At the present time, there are reliable prevalence estimates for the hearing-impaired population (Schein & Delk, 1971), and these will be reported later in this section. However, as Cerva (1977) notes, it is not certain how many people in the United States have developmental disabilities as defined by the Disabled Assistance and Bill of Rights Act of 1975 (P.L. 94-103). Gross estimates differ due to variations in definitions, validity of identification and reporting procedures, and sampling methods.

1. *Developmental Disabilities*

It has been estimated that approximately 3 to 6% of the U.S. population, or between 6 to 12.6 million people, have one or more of the developmental disabilities. The following section presents prevalence estimates for four basic categories of the developmental disabilities.

A. *Autism.* Recent estimates of the prevalence of autism in the general population range from 4.3 per 10,000 (Brask, 1970) to 4.8 per 10,000 (Traffers, 1970; Wing, et. al., 1976). Applying the higher rate to the January, 1977, population of the United States yields a current prevalence figure of 102,960 persons.

Discussing this prevalence rate, Cerva (1977, p. 13) comments:

> Autism is described almost totally as a childhood disability. Most researchers use the term as connoting childhood autism although many children with autism reach adulthood with the same symptoms. These adults are likely to be labeled mentally retarded or mentally ill. This procedure by definition insures that the prevalence rate for autism is highest among children. There is also a historical problem here. Most of the work on autism has occurred in the last 25 years so that the oldest cohort of individuals who were correctly labeled autistic in childhood is now only 30 or 40 years old.

B. Cerebral Palsy. According to a pamphlet distributed by the United Cerebral Palsy Association (1977) 750,000 children and adults in the U.S. have cerebral palsy, and more than 250,000 of them are under 21 years of age. Cerva (1977) quotes these figures, adding that this translates into a rate of .36% (.0036).

C. *Epilepsy.* Estimates of the prevalence of epilepsy in the U.S. population range from less than 1% to 5%. Basing its estimate upon nine studies, the Epilepsy Foundation of America (1975) states that epilepsy has a prevalence rate of 2% in the U.S. Applying this rate to the 1977 U.S. population suggests that there are currently 4,290,000 children and adults with epilepsy.

D. *Mental Retardation.* The American Association on Mental Deficiency has estimated that the prevalence rate for mental retardation is 3%. According to this estimate, then, the January, 1977 U.S. population of 214,500,000 included 6,435,000 mentally retarded persons.

E. *All Developmental Disabilities.* Combining the above population prevalence estimates for autism, cerebral palsy, epilepsy, and mental retardation results in an over-all prevalence rate of 5.4% or a current total of 11,596,000 children and adults. However, many persons have more than one developmental disability, and consequently such persons are counted more than once in the preceding estimates. Cerva (1977) attempts to correct for such overlapping estimates by reducing the combined population prevalence rate to an even 5% for all developmental disabilities. This reduction, then, results in a current estimate of 10,725,000 for the developmentally disabled population in the U.S.

2. *Hearing Impairment*

The prevalence of hearing impairment in the U.S. has recently been studied extensively by the National Association of the Deaf and the Department of Health, Education, and Welfare's Rehabilitation Services Administration (Schein & Delk, 1971). In this nationwide census of deaf people, the investigators reported the following information.

A. *All Hearing Impairments.* Concerning the prevalence and prevalence rates for hearing impairments in the civilian noninstitutionalized population, Schein and Delk (1971) reported 13,362,842 children and adults in the U.S. with some degree of hearing impairment. This represents a prevalence rate of 6,603 per 100,000, or 6.6%.

B. *Significant Bilateral Hearing Impairment.* This category encompasses hearing loss in both ears, with the individual having some difficulty hearing and understanding speech through the better ear (Schein & Delk 1971, p. 133). In this category the investigators reported there were 6,548,842 persons of all ages, or a prevalence rate of 3,236 per 100,000. This represents 3.2% of the total population.

C. *Deafness.* In the deafness category ("inability to hear and understand speech") Schein & Delk (1971) reported a prevalence of 1,767,046 persons of all ages. This is a rate of 873 deaf persons per 100,000 population, or .873%.

a. *Prevocational Deafness.* Schein and Delk (1971) used the classification "prevocational deafness" to refer to all ages at onset of deafness up to 19 years. In this subgroup they reported 410,522 deaf persons, for a prevalence rate of 203 per 100,000 (.203%).

b. *Prelingual Deafness.* This category was used by the investigators to include all deaf persons who became deaf prior to three years of age. A prevalence of 201,626 persons as found in this category, which represents a prevalence rate of 100 per 100,000, or .1%.

In applying the 1971 prevalence rate to the 1977 U.S. population estimate of 214,500,000, the following prevalences should obtain (assuming 1971 rates remain valid for 1977):

Category	Prevalence Rate	1977 Population Estimate
All hearing impairment	6.6%	14,157,000
Significant bilateral	3.2%	6,864,000
Deafness	.873	1,869,580
Prevocational	.203	435,435
Prelingual	.1	214,500

3. *Hearing Impaired/Developmentally Disabled*

There apparently have been no reported studies of the prevalence of hearing impairment in combination with the four developmental disabilities in the U.S. population. Even when hearing impairment and one of the developmental disabilities are considered, most related studies have been restricted in methodology. The problem seems to be essentially one of diagnosis and sampling. The hearing impaired/developmentally disabled (HIDD) population represents an especially hard-to-diagnose group. Superimposed on the communication problems inherent in developmental disabilities are the communication problems related to loss of hearing. Symptoms overlap among these classifications, and many developmentally disabled persons fail to respond to sophisticated audiometric assessment procedures. While evoked response audiometry represents a breakthrough in testing nonresponsive persons, the methodology currently is not readily available for widespread use due to manpower scarcity. The following information is presented with these limitations in mind.

A. *Hearing Impaired/Autistic.* There is currently very little information available concerning this population due to two problems. Differentiating autism per se from other diagnostic classifications presents one problem. Another problem is that autistic persons exhibit severe communication deficits that can be differentiated from the problems caused by hearing loss only by sophisticated audiometric

procedures. These difficulties have up to now precluded reliable studies of the prevalence of HIA. However, if we assume that the prevalence rate of hearing impairment among the U.S. populations is similar for autistic persons, then we may expect 6.6% (Schein & Delk, 1971) of autistic persons who comprise 4.8 per 10,000 of the 1977 U.S. population of 214,500,000, to be hearing impaired.

$$(.066) \times \frac{4.8}{10,000} \times (214,500,000) = 6,795$$

Hearing Loss Rate	Autism Rate	U.S. Population (1977)	HIA Persons

Thus, of the estimated 102,960 autistic persons in the U.S., 6,795 may be hearing impaired.

B. *Hearing Impaired/Cerebral Palsied.* Although the United Cerebral Palsy Association (1977) notes that cerebral palsy often is accompanied by hearing and/or speech problems, there is little information on the prevalence of hearing impairment among persons with cerebral palsy.

In the Schein and Delk (1971) national census of the deaf, .9% of the respondents reported having cerebral palsy. As will be seen below, this rate is more than double the prevalence rate for cerebral palsy among the hearing population (.36%).

The etiologies of cerebral palsy are often causative factors of hearing loss, and on this basis we may reasonably estimate that the prevalence of hearing loss is higher among the cerebral palsied than among the general population. The following estimate, then, should be viewed as a significantly low one.

$$(.066) \times (.0036) * (214,500,000) = 50,965$$

Hearing Loss Rate	C.P. Rate	U.S. Population (1977)	HICP Persons

According to the above extrapolation, then, there were at least 50,965 hearing-impaired cerebral palsied persons in the U.S. in January, 1977.

C. *Hearing-Impaired/Epileptic Persons.* Hearing impairment among persons who are epileptic has not been studied to an appreciable extent due to the fact that the epileptic population itself has not been adequately studied in terms of numbers and other characteristics. In the absence of more definite information, then, the prevalence rate for hearing impairment among the general population may be applied to the epileptic population.

(.066)	X	(.02)	X	(214,500,000)	=	283,140
Hearing Loss Rate		Epilepsy Rate		U.S. Population		HIE Persons

Thus, among this country's 4,290,000 persons with some form of epilepsy, at least 283,140 have some degree of hearing loss. Since some of the etiologies of epilepsy also cause hearing loss, we may consider 283,140 to represent an underestimation.

D. *Hearing-Impaired/Mentally Retarded Persons.* Hearing impairment among mentally retarded persons has been the subject of several recent studies which will be reported in this section. However, the limitations of each study are such that drawing conclusions from them regarding national prevalence rates appears to be questionable for the reason to be given.

According to Schein and Delk (1971, p. 123), 1.6% of the respondents surveyed in a national census of the deaf reported also having mental retardation. Although an excellent study,the Schein and Delk (1971) results were based upon a census of noninstitutionalized citizens. Accordingly, the results are not applicable in considering the total HIMR population since so many of this population are in institutions.

According to a report of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded (Scheerenberger, 1976, p. 14), 2,806 or 2.8% of the 100,283 residents of public residential facilities for the mentally retarded were reported as deaf and 1,600 (1.6%) were reported as blind and deaf. However, the 237 public residential facilities reporting for the 1975-1976 year classified 74% of their residents as severely to profoundly retarded. In view of the difficulty inherest in audiological assessment of the severely and profoundly retarded, the validity of these reported data is questionable. For example, it was reported in 1961 that a mail survey indicated that the prevalence of hearing loss among the institutionalized retarded ranged from 0% to 50%. Rittmanic (1971), on the basis of a review of 27 surveys, also reported variation in reported prevalence of hearing loss, which ranged from 8% to 56%. Brannan, Sigelman, and Bensberg (1975) surveyed 212 state facilities for the mentally retarded, with 158 of these facilities returning more or less complete survey forms. Of these 158, 111 provided estimates of the hard-of-hearing and the deaf mentally retarded populations. There were 98,034 residents in these 111 institutions. Among these residents, 9,343 (9.53%) were reported as hearing impaired, or deaf, 7,100 (7.24%) were classified as hard of hearing; and, 2,243 (2.29%) were classified as deaf. However, estimates varied from institution to institution, with such estimates ranging from 0.21% to 35.4% for hard-of-hearing residents and 0% to 12.17% for deaf residents.

Although the Brannan et. al. (1975) study represents one of the better studies in the field, the authors conclude:

However, the validity of these incidence figures was jeopardized by varying definitions of hearing impairment, approximate census figures, and incomplete survey data.

Healey (1975) notes the wide range of prevalence estimates for the HIMR population, and suggests that a 10% rate may obtain. It is clear that previous studies have failed to result in a reliable prevalence rate estimate for the HIMR population. Considering the available data, two tentative rates may be considered pending further findings:

1. Applying the 10% rate suggested by Healey (1975, p. 1) to the 1977 U.S. population of mentally retarded persons yields a current prevalence of 643,500 (6,435,000 x .10).

2. Applying the 6.6% prevalence rate for hearing impairment (Schein & Delk, 1971) to the 1977 U.S. population of mentally retarded persons (6,435,000) results in a current prevalence of 424,611 HIMR persons.

In view of the fact that many of the causes of mental retardation also lead to hearing impairment, it is probable that the first estimate above (643,500) is closer to the true prevalence of hearing impairment and mental retardation.

E. *The HIDD Population.* The hearing-impaired/developmentally disabled population, according to the tentative estimates that have been derived from the above calculations, is composed of the following numbers:

Hearing Impaired/Autistic	6,795
Hearing Impaired/Cerebral Palsied	50,965
Hearing Impaired/Epileptic	283,140
Hearing Impaired/Mentally Retarded	643,000
Hearing Impaired/Developmentally Disabled	983,900

Since many HIDD persons have more than one developmental disability, the estimate of 983,900 should be corrected downward. How much downward correction is appropriate cannot now be determined.

INDIVIDUALIZED DATA BASE (I.D.B.) FINDINGS

The Individualized Data Base (IDB) project, operated by the U.C.L.A. Neuropsychiatric Institute's Research Group, has as its major purpose the designing and operating of a data system capable of evaluating services for mentally retarded, cerebral palsied, and epileptic individuals in sample states (Eyman and Boroskin, 1976). It began in 1972, and continues to operate at present. A total of 82 agencies in nine states had contributed to the data base by September, 1975 (Eyman and Boroskin, 1976, p. 6).

The I.D.B., in a personal communication to the author in 1977, reported the following data:

- Among 2,835 clients of the Inland Counties (California) Regional Center for the Mentally Retarded, 243 clients were reported as having "some difficulty in hearing," "great difficulty in hearing," or "no hearing." This represents a prevalence rate greater than 8%.

- Among the 1,700 residents of the Pacific State Hospital in Pomona, California, a total of 251 persons had some degree of hearing loss. This is a prevalence rate of 14%.

The I.D.B. data tend to confirm the fact of the variability of prevalence estimates encountered with developmentally disabled subpopulations while suggesting the validity of Healey's (1975) estimate on the HIMR population.

PROJECT FINDINGS

Population findings by the project consist of data obtained from other Arizona agencies and data obtained directly by project staff from its direct service operations (audiological assessments, educational assessments, counseling, etc.)

Arizona's Bureau of Mental Retardation. In 1977, the Bureau of Mental Retardation indicated that approximately 900 of its 4,000+ developmentally disabled clientele were reported via I.D.B. statistical summaries to be communicatively handicapped by hearing impairment. This represents almost 25% of the total B.M.R. clientele population. However, a more definitive report the following year (1978) showed approximately 399 out of a selected population of 2,446 as "hearing impaired". The resulting prevalence rate, 16.3%, is lower than the 1977 figure but quite substantially higher than the 66% rate of hearing impairment in the general population as well as the 10% rate for hearing impairment among the mentally retarded as estimated by Healey (1975).

Public Schools, State Department of Education, Others. Public schools in Arizona, the Arizona Department of Education, the Arizona State School for the Deaf and the Blind, and the Arizona Bureau of Rehabilitation Services could not identify the numbers of HIDD persons within their systems. The reasons for this appear to boil down to (1) there has been no clearcut administrative reason for keeping such data, (2) there is no statistical procedure in these systems for identifying HIDD persons, and (3) in many cases diagnostic processes are unavailable for identifying HIDD conditions.

Model Demonstration Program. The staff of the Model Demonstration Program provided direct client services in Arizona during the period January, 1977, through approximately May, 1978, as part of its demonstration activities (see Chapter 6). During this 17 month span of time, more than 400 children and adults were served.

The following sections, prepared by Michael Milone, report selected information on these individuals.

Personal characteristics of the 400+ individuals referred for service to the MDP from October, 1976, to May, 1978, at least partial information is available on 368 persons. There were 139 adults (37.9%) and 229 children (62.1%) in this group. Figure 1 represents client age.

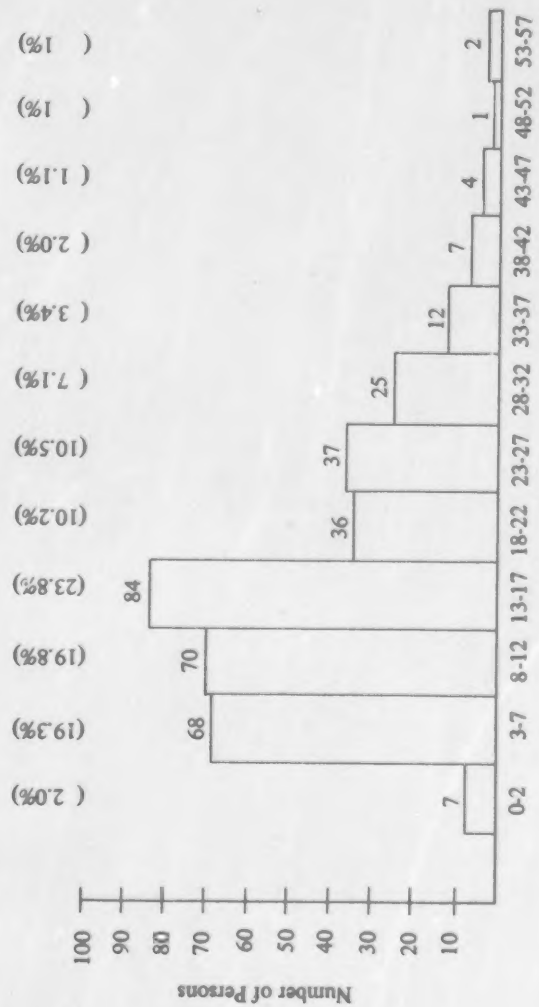


Figure 1. Distribution of MDP clients' ages October, 1976-May, 1978

The distribution in Figure 1 conforms closely to the age distribution for mental retardation (Gruenberg, 1964), but differs markedly from the age distribution for institutionalized mentally retarded persons (Brauman, et al, 1975), persons with a hearing impairment (Schein & Delk, 1974), epileptic individuals (Kurland, et al, 1973), and autistic children. This pattern is logical, given the following facts:

a. The vast majority of persons in the Model Demonstration Program sample were mentally retarded (85.5%).

b. Less than 30% of the current sample was institutionalized, while only 21.9% were epileptic.

c. A diagnosis of autism usually reverts to one of schizophrenia upon reaching adulthood.

The epidemiological comparisons drawn above are risky, given the non-random nature of the MDP's sample. It is more likely that Figure 1, rather than representing the frequency of occurrence of a physical condition or conditions, reflects service needs. Very young HIDD children, ages 0 to 2 years, for example, may not have had much opportunity to manifest specific behavioral discrepancies, while older HIDD adults may be considered "beyond help." Very few individuals in these age groups were referred for service. School age children and young adults, on the other hand, require either educational or rehabilitation services. Because of their multiple disabling conditions, they probably lagged beyond their peers, and were referred for supplemental service to what seemed to be an appropriate agency (MDP).

The ratio of male to female HIDD persons is approximately 3 to 2 (Table 1). As can be concluded from Table 1, this finding is consistent for both children and adults. For the remainder of this paper, age 18 will serve as the dividing line between childhood and adulthood.

Table 1
Ratio of males to females for
children and adults

	Adults		Children		Total	
	n	%	n	%	n	%
Female	55	39.6	83	36.2	138	37.5
Male	84	60.4	146	63.8	230	62.5
Total	139	100.0	229	100.0	368	100.0

Schein & Delk (1974) report a similar male-female ratio for significant bilateral hearing loss. Cerebral palsy and epilepsy also appear with substantially higher frequency in males than females (U.S. Office of Education, 1970), while mentally retarded males outnumber their female peers by a slight margin (Hewett & Forness,

1974). In light of these data and the consistency of the findings in Table 1, it seems reasonable to conclude that there are more HIDD males than females.

The racial characteristics of the MDP sample are summarized in Table 2. As is quite evident, there are rather large charges in percentages between childhood and adulthood, making a general interpretation difficult. To compound this difficulty, there is little conformity between Table 2 and a similar table describing Arizona's total population and school age handicapped populations. This table is contained in Appendix A of this report.

The most confident interpretation that can be made from the data in Table 2 is that with the exception of black children, non-white children and adults were overrepresented among the MDP's clients. This interpretation is consistent with the almost universal finding that minority group individuals constitute larger proportions of the mentally retarded population than they do of the total population. The reasons for this overrepresentation are amply discussed in the literature and need not be presented here.

Table 2
Racial characteristics of the MDP sample

	Adults		Children		Total	
	n	%	n	%	n	%
Black	17	12.9	8	3.6	25	7.1
Caucasion	84	63.6	130	58.6	214	60.5
Hispanic	14	10.6	45	20.3	59	16.7
Native American	10	7.6	38	17.1	48	13.6
Oriental	1	1.0			1	1.0
Mixed	6	4.5	1	1.0	7	2.0
Total	132	100.0	222	100.0	354	100.0

It may be appropriate at this time to interject a comment relating to the large differences in the proportions of child and adult referrals who are Hispanic or Native American. In Arizona, it appears to be culturally acceptable for Hispanic or Native American individuals to seek help for handicapped *children*. Upon reaching *adulthood*, however, there appears to be some reluctance about seeking habilitation services. Consequently, handicapped adults within the Hispanic and Native American populations disappear for all intensive purposes and service beyond the traditional human service delivery system. This culturally encouraged behavior may contribute to the change pattern evidenced in Table 2.

Service Characteristics

As can be seen in Table 3, the clients who were referred for service to the MDP lived in a variety of settings. The predominant residences, accounting for over 80% of client living situation, were institutions and natural or adoptive parents.

A surprising feature of Table 3 is the small proportion (less than 15%) of HIDD adults living independently, in group homes, or in supervised apartments. Given the increasing emphasis that is being placed on deinstitutionalization, it seems as if the normalization of HIDD adults is a low priority issue with professionals. Two factors that contribute to this situation are the expense associated with deinstitutionalizing a severely handicapped, low incidence population, and the lack of staff training and client-use materials for HIDD persons.

A second feature of interest in Table 3 is the change in percentage of parents who are willing to support their HIDD child. The large decrease between childhood and adulthood may represent the exhaustion of parents after years of caring for their severely handicapped child who has grown up.

The significant proportion of parents (29.2%) who continued to support their HIDD offspring into adulthood is encouraging. Although the dependent nature of parent-adult child relationships is a potentially negative characteristic, the fact that almost 1/3 of the parents of adult HIDD persons are willing to maintain a supportive relationship is a trend that bodes well for their future.

The day placements of the clients referred to the MDP are summarized in Table 4. The preponderence of adult clients were found in institutions for the mentally retarded or in sheltered workshops. Quite apparent, however, is the variability observed in the placement of the children. This variability indicates that no single educational program was primarily responsible for educating HIDD or other severely handicapped hearing impaired children.

The large proportion (almost 30%) of referrals from public schools implies that efforts were being directed at mainstreaming HIDD students into comparatively normalized settings. This practice, however, seems to have engendered difficulties in that public school personnel were referring a large number of students for service to the MDP.

From Table 4, it is also apparent that institutions for the mentally retarded were enrolling a significant proportion of HIDD children and adults. Over 25% of the referrals received by the MDP were from institutions for the mentally retarded. This large proportion of referrals tends to refute the commonly held opinion that residential schools educate the majority of HIDD persons; this substantiates previous conclusions of the MDP staff concerning residential school services to HIDD persons (Milone, Perine, and Stewart, 1978).

A summary of the suspected and confirmed disabilities of MDP referrals is presented in Table 5. The categories of disability listed under the headings of

Table 3
Breakdown of client residence

	Adults		Children		Total	
	n	%	n	%	n	%
Natural or adoptive parents	40	29.2	167	75.6	207	57.8
Foster parents	2	1.5	3	1.4	5	1.4
Institution, mentally retarded	68	49.6	22	10.0	90	25.1
Residential school, hearing impaired	5	3.6	23	10.4	28	7.8
Independent living	6	4.4			6	1.7
Group home	11	8.0	5	2.3	16	4.5
Supervised apartment	3	2.2			3	1.0
Other	2	1.5	1	1.0	3	1.0
Total	137	100.0	221	100.0	358	100.0

Table 4
Breakdown of client day placements

	Adults		Children		Total	
	n	%	n	%	n	%
Institution, mentally retarded	60	43.2	38	16.6	98	26.6
Residential school, hearing impaired	7	5.0	61	26.6	68	18.5
Adult workshop	60	43.2	8	3.5	68	18.5
Preschool			21	9.2	21	5.7
Public school class, mentally retarded	1	.7	25	10.9	26	7.1
Public school class, hearing impaired			4	1.7	4	1.1
Public school resource room	1	.7	31	13.5	32	8.7
Public school regular class			5	2.2	5	1.4
Public school HIDD class			3	1.3	3	.8
Private school	1	.7	10	4.4	11	3.0
Special education school	1	.7	10	4.4	11	3.0
State hospital	1	.7			1	.3
Community	1	.7			1	.3
None	6	4.3	13	5.7	19	5.2

Table 5
Suspected and confirmed disabilities

	Adults		Children		Total	
	n	%	n	%	n	%
Suspected disability						
Hearing impairment	137	98.6	222	97.4	359	97.8
Mental retardation	131	94.2	185	81.1	316	86.1
Autism	1	.7	13	5.7	14	3.8
Epilepsy	35	25.2	33	14.6	68	18.5
Cerebral palsy	20	14.4	31	13.6	51	13.9
Visual impairment	17	12.2	22	9.6	39	10.6
Orthopedic/other health	18	12.9	18	7.9	36	9.8
Learning disability	2	1.4	1	.4	3	.8
Emotional disturbance/behavior disorder	5	3.6	1	.4	6	1.6
Confirmed disability						
Hearing impairment	76	66.7	61	45.5	137	55.2
Mental retardation	122	94.6	125	78.6	247	85.8
Autism	1	.8	9	5.7	10	3.5
Epilepsy	334	26.4	29	18.2	63	21.9
Cerebral palsy	18	14.0	26	16.4	44	15.3
Visual impairment	15	11.6	20	12.6	35	12.2
Orthopedic/other health handicap	17	13.2	16	10.1	33	11.5
Learning disability	1	.8	1	.6	2	.7
Emotional disturbance/behavior disorder	5	3.9	1	.6	6	2.1

suspected and confirmed are not mutually exclusive; column totals do not equal 100 percent, and are therefore not reported.

The categories of mental retardation and hearing impairment are far and away the largest. Hearing impaired mentally retarded persons constituted the largest proportion of clients referred to the MDP, and also account for the largest percentage of the national HIDD population.

Table 5 suggests that the accuracy of referral for some disabilities was not as high as that of other disabilities, and in fact, was not high at all. There were, for example, 359 persons referred for a suspected hearing impairment; of this number, only 137 were confirmed, resulting in a "hit" percentage of just over 38 percent. This figure may be misleading, however, in that a number of referrals were never processed, and could not therefore be confirmed, Table 5 does not account for those initial referrals who were either withdrawn or were in progress at the time of the data analysis.

The actual agreement between confirmed and suspected disabilities, disregarding unprocessed cases, is reported in Table 6. With the exception of hearing impairment, there was very high referral reliability. The low percentage (55.7%) for hearing impairment lends credence to the contention that hearing impairment is quite difficult to diagnose through simple observation. Conditions such as mental retardation, autism, certain categories of emotional disturbance, and many learned behaviors result in symptoms that are often associated with hearing impairment. *This finding suggests that clinical audiometry is an essential service when serving developmentally disabled persons.*

Table 6 also shows that the accuracy of preliminary diagnosis of hearing impairment is higher for adults than for children. It is likely that by the time the multiply handicapped person reaches adulthood, the conditions whose symptomatology resembles that of deafness have been either confirmed or eliminated. In addition, it is probable that an audiometric evaluation will have been completed by the time the person reaches adulthood, thus lending the weight of clinical diagnosis to observational judgment.

The agreement between confirmed and suspected disabilities for males and females is shown in Table 7. There seems to be little difference in accuracy of referral for these groups.

Table 8 summarized accuracy of referral data within each category of day placement. It is readily apparent that the greatest variability in referral accuracy is associated with hearing impairment. While referrals from residential schools for hearing impaired persons were completed with perfect accuracy, those from public schools and institutions for mentally retarded persons were correct only 40% of the time. It is reasonable to assume that the personnel in public schools and institutions for the mentally retarded are less familiar with the specific behavioral concomitants of hearing impairment or that the clients in these respective settings have behavior that cannot be clearly attributed to one disability.

Table 6
Agreement between confirmed and suspected disabilities,
adults versus children*

	Adults		Children		Total	
	n	%	n	%	n	%
Hearing impairment	76	66.1	60	46.5	136	55.7
Mental retardation	107	98.1	101	95.3	208	96.7
Autism	1	100.0	7	100.0	8	100.0
Epilepsy	28	100.0	23	100.0	51	100.0
Cerebral palsy	16	94.1	21	95.5	37	94.9
Visual impairment	13	92.9	14	100.0	27	96.4
Orthopedic/other health handicap	16	94.1	13	100.0	29	96.7
Learning disability	1	50.0	1	100.0	2	66.7
Emotional disturbance/behavior disorder	4	80.0	1	100.0	5	83.3

*The figure reported in the percent column represents the ratio of confirmed to suspected disability in each category, for cases that were completely processed.

Table 7
Agreement between confirmed and suspected disabilities,
for males and females

	Female		Male		Total	
	n	%	n	%	n	%
Hearing impairment	55	59.8	82	53.6	137	55.9
Mental retardation	79	95.2	130	97.7	209	96.7
Autism	22	100.0	6	100.0	8	100.0
Epilepsy	17	100.0	34	100.0	51	100.0
Cerebral palsy	12	85.7	25	100.0	37	94.9
Visual impairment	11	91.7	16	100.0	27	96.4
Orthopedic/other health handicap	13	92.9	16	100.0	29	96.7
Learning disability	2	66.7			2	66.7
Emotional disturbance/behavior disorder	3	75.0	2	100.0	5	83.3

*The figure reported in the percent column represents the ratio of the confirmed suspected disability in each category, for cases that were completely processed.

Table 8
Agreement between confirmed and suspected disabilities
by day placement*

	Institution for the mentally retarded		Residential school for the hearing impaired		Adult workshop		Public school	
	n	%	n	%	n	%	n	%
Hearing impairment	29	40.8	18	100.0	45	77.6	26	40.0
Mental retardation	69	100.0	16	100.0	52	98.1	44	91.7
Autism			1	100.0			4	100.0
Epilepsy	19	100.0	1	100.0	17	100.0	8	100.0
Cerebral palsy	13	100.0	3	75.0	10	100.0	4	100.0
Visual impairment	6	100.0	1	100.0	14	100.0	4	100.0
Orthopedic/other health handicap	8	100.0	2	100.0	12	100.0	4	100.0
Learning disability							1	100.0
Emotional disturbance/behavior disorder					3	100.0	1	100.0

*The figure reported in the percent column represents the ratio of confirmed to suspected disability in each category, for cases that were completely processed.

Table 9
Eligibility figures broken down by age

	Adults		Children		Total	
	n	%	n	%	n	%
Ineligible	37	28.5	84	49.1	121	40.2
Eligible	79	60.8	48	28.1	127	42.2
In progress	14	10.8	39	22.8	53	17.6
Total	130	100.0	171	100.0	301	100.0

Table 10
Eligibility figures broken down by sex

	Female		Male		Total	
	n	%	n	%	n	%
Ineligible	42	37.2	79	41.8	121	40.1
Eligible	51	45.1	77	40.7	128	42.4
In progress	20	17.7	33	17.5	53	17.5
Total	113	100.0	189	100.0	302	100.0

Final eligibility figures are broken down by age and sex in Tables 9 and 10. The data in these tables, interpreted in the light of the findings reported in Tables 6 and 7, imply that the accuracy of referrals for adults is much greater than that for children, and that there is little difference in diagnostic and referral accuracy between males and females.

The eligibility figures and correspondence rates between suspected and confirmed disabilities cited in the previous paragraphs lead to the conclusion that some means must be developed by which the reliability of referrals of suspected hearing impaired persons can be increased. A low correspondence between suspected and confirmed hearing impairment (Tables 6 through 8) and a comparatively small percentage of eligible clients (Tables 9 and 10) implies a tremendous waste of personal and financial resources, since the same effort must be expended to process ineligibile referrals as is expended on eligible referrals. What is needed is a screening tool or procedure by which correspondence and eligibility rates can be increased.

The reasons for which clients were referred to the MDP are summarized in Table 11. Audiometry was the most frequent referral reason for both children and adults, attesting to the scarcity of comprehensive audiometric services in the state of Arizona, particularly in rural areas.

Table 11
Reasons for which clients were referred to the MDP*

Adult	Adults		Children		Total	
Referral reason	n	%	n	%	n	%
Audiometry	79	56.8	136	60.2	215	58.9
Advocacy	2	1.4			2	1.0
Counseling	2	1.4			2	1.0
Psychoeducational assessment	3	2.2	39	17.3	42	11.5
Classroom assistance	3	2.2	16	7.1	19	5.2
Placement	2	1.4	8	3.5	10	2.7
Identification registry	25	18.0	6	2.7	31	8.5
Other	23	16.5	21	9.3	44	12.1

*The principal reason for referral is identified in the table. Two or more principal reasons were subsumed under the heading "other".

Psychoeducational assessment and classroom assistance, although they were the second and fourth most frequent reasons for referral, were not actually of major initial importance. The chief factor contributing to the low emphasis on diagnosis

Table 12
Sources of referrals to the MDP

Source	Adults		Children		Total	
	n	&	n	%	n	%
Bureau of Mental Retardation	79	56.8	54	23.6	133	36.1
Residential school, hearing impaired	7	5.0	80	34.9	87	23.6
Adult workshop	28	20.1	4	1.7	32	8.7
Preschool			18	7.9	18	4.9
Public school	4	2.9	49	21.4	53	14.4
Private school	1	1.0	11	4.8	12	3.3
Parent	1	1.0			1	1.0
Vocational rehabilitation	11	7.9			11	3.0
Community counseling center	3	2.2			3	1.0
State or local health department	1	1.0	4	1.7	5	1.4
Bureau of Indian Affairs			6	2.6	6	1.6
Other	4	2.9	3	1.3	7	1.9

and classroom assistance was probably the lack of organization for initiating referrals by the schools.

Until an appropriate audiometric evaluation is completed, there remains some question as to the presence of a hearing impairment. Once a final decision is made that the child is hearing impaired, then psychoeducational diagnosis and program planning can follow. Although no formal data were kept, it appears as if requests for service *following* an audiometric assessment consisted primarily of psychoeducational evaluation and classroom assistance. The frequency of these follow-up requests suggests that few widely-available diagnostic or curriculum resources are readily available to teachers for use with HIDD persons.

Referrals to the MDP came from various sources, chief among which were the Bureau of Mental Retardation, the state residential school for hearing impaired children, and the public schools (Table 12). The frequency of referrals from these sources seemed to be proportional to the number of clients served by each agency, suggesting also that no single agency evidenced indepth strength in serving HIDD persons. Such strength would be signaled by an exceptionally low if any referral rate.

The numbers of referrals that were made to the MDP during each year of its existence are shown in Table 13. This information is presented for two reasons. First, the pattern reflects the change in emphasis of the MDP. Year 1 (1976) was the beginning year, in which efforts were directed primarily at staff acquisition, locating suitable office space, and so on. In 1977 (Year II), the MDP was primarily concerned with providing direct services and received over 80% of its referrals. By mid-1978, the MDP had switched from a direct service mode to developing and validating materials, and rechanneled referrals for direct services to appropriate state and local agencies and schools.

Table 13
Referrals to the MDP broken down by year

	Adults		Children		Total	
	n	%	n	%	n	%
1976	6	4.3	2	1.0	8	2.1
1977	123	88.5	187	81.7	310	84.2
1978	10	7.2	40	17.5	50	13.6

The second reason for including Table 13 is to point out the inadequacies of services before the MDP was founded and the potential for lack of services in the future. Although the MDP did its best to promote service to HIDD persons through assisting appropriate schools and agencies, there is no guarantee that these services will continue once the MDP's funding expires. It is possible that once the influence of the MDP has been removed, the pattern of underservice and neglect that characterized the situation of the HIDD person before 1976 will reappear.

Table 14
Frequency of multiple disabilities,
adults versus children

Number of disabling conditions	Adults		Children		Total	
	n	%	n	%	n	%
0	1	.9	8	6.1	9	3.6
1	28	24.1	50	37.9	78	31.5
2	50	43.1	47	35.6	97	39.1
3	20	17.2	18	13.6	38	15.3
4	11	9.5	3	2.3	14	5.6
5	5	4.3	5	3.8	10	4.0
6	1	.9	1	.8	2	.8

Table 15
Frequency of multiple disabilities,
males versus females

Number of disabling conditions	Female		Male		Total	
	n	%	n	%	n	%
0	4	4.3	5	3.2	9	3.6
1	25	26.9	53	34.0	78	31.3
2	39	41.9	59	37.8	98	39.4
3	16	17.2	22	14.1	38	15.3
4	4	4.3	10	6.4	14	5.6
5	3	3.2	7	4.5	10	4.0
6	2	2.2			2	.8

Table 16
Frequency of multiple disabilities, by day placement

Number of disabling conditions	Institution for the mentally retarded		Residential school for the hearing impaired		Adult workshop		Public school	
	n	%	n	%	n	%	n	%
0	1	1.4					7	10.8
1	24	33.8	2	11.1	12	20.3	29	44.6
2	28	28.6	9	50.0	22	37.3	23	35.4
3	11	15.5	6	33.3	13	22.0	4	6.1
4	5	7.0	1	5.6	3	5.1	1	1.5
5	1	1.4			8	13.6	1	1.5
6	1	1.4			1	1.7		

Table 17
Coincidence among disabilities

	Mental Retardation	Autism	Epilepsy	Cerebral Palsy	Visual Impairment	Orthopedic/other health handicap	Learning Disability	Emotional Disturbance
Hearing impairment	116	5	25	24	23	24	2	3
Mental retardation		7	56	37	31	25	1	5
Autism			0	2	1	1	0	1
Epilepsy				17	16	13	0	2
Cerebral palsy						3	0	2
Visual impairment						12	0	2
Orthopedic/other health handicap							0	0
Learning disability								1
Emotional disturbance/ behavior disorder								

Multiple Disabilities

The incidence of multiply disabling conditions among the clients referred to the MDP is shown in Tables 14 through 16. Adults seem to show a higher frequency of two or more disabilities than do children, while females exhibit slightly more multiply disabling conditions than males. Institutionalized referrals showed the highest frequency of multiple disabilities, followed by adult workshop clients, residential school students, and public school children.

Table 18 summarizes the co-incidence of various pairs of disabilities. The categories are not mutually exclusive, so the marginal totals are not reported. Hearing impairment in combination with mental retardation was the most frequent multiple disability, followed by mental retardation and epilepsy. Information on frequency and rank of multiply disabling conditions is reported in Table 18.

Table 18
Frequency and rank of the 10 most often occurring multiple disabilities

Multiple Disability	Frequency	Rank
Hearing impairment/mental retardation	116	1
Mental retardation/epilepsy	56	2
Mental retardation/cerebral palsy	37	3
Mental retardation/visual impairment	31	4
Mental retardation/orthopedic, other health	25	5
Hearing impairment/epilepsy	25	6
Hearing impairment/cerebral palsy	24	7
Hearing impairment/orthopedic, other health	24	8
Hearing impairment/visual impairment	23	9
Epilepsy/cerebral palsy	17	10

Appendix A

Arizona's population
by race

Arizona's total population and school-age handicapped population by race
1974

	Total Population		School-age Handicapped	
	n	%	n	%
Black	53,344	3.01	815	8.47
White	1,482,645	83.73	5,759	59.84
Hispanic	122,303	6.91	2,335	24.26
Native American	95,812	5.41	637	6.62
Oriental	7,425	0.42	36	0.37
Other/mixed	9,271	0.52	42	0.44
Total	1,770,800	100.00	9,624	100.00

Sources: U.S. Bureau of the Census. *1970 Census of Population: General Population Characteristics. Arizona. PC(1)-84.*

Arizona Department of Education, Division of Planning and Evaluation. *Racial-Ethnic Survey, Winter 1973.*

SUMMARY

Chapter 5 has presented a comprehensive discussion of important characteristics of hearing impaired developmentally disabled persons. Although the data on HIDD persons has not been derived from rigorous research, it should serve a strong heuristic function in the future as behavioral scientists seek more definitive population parameters for educational and rehabilitation planning purposes.

MDP experience with HIDD persons of all ages and circumstances yielded important information concerning the current needs of this population as well as what is happening to some of them in typical schools and agencies at this time.

The Disabled Assistance and Pill of Rights Act of 1975 (P.L. 94-103) provided the basic definition of the term, developmentally disabled, for the purposes of this project. However, this definition has been substantially modified as a result of Title V of P.L. 95-602 (Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, 92 Stat. 2955). Title V, otherwise entitled

"Amendments to the Developmental Disabilities Services and Facilities Construction Act," states, in regard to definitions:

> (7) The term "developmental disability" means a severe, chronic disability of a person which:
>
> (A) is attributable to a mental or physical impairment or combination of mental and physical impairments;
> (B) is manifested before the person attains age twenty-two;
> (C) is likely to continue indefinitely;
> (D) results in substantial functional limitations in three or more of the following areas of major life activity:
> (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency, and
> (E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.
>
> Public Law 95-602, Nov. 6, 1978

This definition is a functional one rather than a categorical one such as P.L. 94-103. The emphasis is upon behavioral or measurable functions as opposed to medical/psychological classifications (e.g., cerebral palsy, autism, etc.). The new criteria outlined above mean that many more hearing impaired persons may be classified as developmentally disabled than have been in the past. Criteria (7) (D) (ii), (7) (D) (iii), and (7) (D) (vi), for example, could be met by a majority of the hearing impaired population. Hence, in the years ahead, we may expect to find the hearing impaired developmentally disabled population to be significantly larger than has been estimated by the Model Demonstration Program.

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CHAPTER 6

SERVICES PROVIDED BY THE MODEL DEMONSTRATION PROGRAM

During the three years in which the Model Demonstration Program was in operation (October, 1976 – September, 1979), the project staff designed, developed, and operated a constellation of direct client services having two goals. The first goal was to assist *other* schools and agencies to enhance their own services for HIDD persons. The second goal was to provide special services that were not *readily* available anywhere in the state. The general purpose of these activities was to identify gaps in services and to demonstrate how these gaps could be effectively filled to the advantage of HIDD persons. The findings of these efforts, in turn, could be published and disseminated for replication in other parts of the country.

MDP BASIC SERVICES

The Model Demonstration Program initially employed service personnel qualified to provide information and referral assistance, parent guidance and counseling, audiological assessment and referral, educational assessment, advocacy, and, where necessary, funds for the purchase of specialized diagnostic/treatment services (such as neurological assessment, cardiac evaluations, ophthalmological assessment, and psychological assessment). Ancillary services included instructional media services, program evaluation and development, and program design consultation.

In addition, MDP contractual funds were employed to study the educational model used at the Arizona Diagnostic, Treatment, and Education Center in Tucson. These funds were used to hire a special staff for demonstration purposes. This subproject will be described in a later section.

Audiological services and personal adjustment services were purchased by the MDP for HIDD persons at the Arizona Training programs in Phoenix and Coolidge, respectively, in an effort to demonstrate the contributions of such services in these settings.

The operation of these service elements are described later in this chapter.

Casefinding and Referral

Casefinding and referral activities were critical aspects of the work of the Model Demonstration Program since, obviously, an individual who needs assistance cannot

be served unless properly identified by the service agency *and* brought to the service. The MDP vigorously pursued casefinding and referral activities via conference announcements, presentations, brochures, letters, personal contacts, and various publication articles. These efforts were highly rewarding in terms of members served during the life of the MDP direct services component, for during this period of time more than 1,200 clients were direct beneficiaries of MDP-sponsored activities.

Chapter 5 has indicated the sources of referrals of MDP clientele. However, to reinforce the MDP belief that professionals are generally unaware of the true status of services for HIDD adults, the tables on the following pages are introduced. These tables clearly substantiate the belief that existing state and local agencies, contrary to popular belief, are *not* meeting the needs of HIDD persons (see the Chapter 4 discussion of the January, 1977, HIDD Needs Assessment Workshop). Moreover, rather than being a resource mainly for public schools or generic service agencies, the Model Demonstration Program was a primary resource for *special* facilities and schools whose service focus was already upon the hearing impaired, developmentally disabled, and/or multiply handicapped. For instance, 46 of the 104 referrals, or 44% of the total number of adult referrals, came from the Arizona Training Program, Tucson.

TABLE 1

HIDD adult referrals, by source, to the Model Demonstration Program: 11/76-1/78

Source of Referral	Number of Referrals
Arizona Training Program, Tucson	46
Vocational Rehabilitation	15
Garden Park Enterprises	8
Arizona Training Program, Coolidge	7
Goodwill Industries, Tucson	6
New Horizons Foundation	6
Bureau of Mental Retardation (non-ATP program)	2
Beacon Foundation	4
Hozhoni Foundation	2
Community Outreach Program for the Deaf	2
Nogales Health Department	1
Resources Services	1
Arizona School for the Deaf and the Blind	1
UA Rehabilitation Center	1
Maricopa County Public Defender's Office	1
Parent	1
Total Referrals	104*

*Males, 59; females, 45; age range 17-52 years.

TABLE 2

Services requested by referring sources: 11/76-1/78

Nature of Service Requested		Number of Requests
Audiological		
a)	Evaluation	51
b)	Screening	10
c)	Records Review	3
d)	Hearing and check along	2
e)	Speech reading assistance	1
	Total Audiological	67
Counseling and Guidance		25
Job Placement		1
Program Development		15
Psychological Evaluation		4
Program Monitoring		1
Technical Assistance		6
	TOTAL	119

Audiological Screening, Assessment

During the first two years of the project, a mobile evaluation unit was deployed statewide to provide both audiological assessment and educational assessment services to HIDD referrals in rural areas and in urban settings that did not have access to such services due to limitations in available services and/or personnel expertise. The third year the unit was deployed statewide solely for use in audiological assessments under a formal joint contract with the Division of Developmental Disabilities-Mental Retardation Services (formerly Bureau of Mental Retardation).

Referrals were made to the MDP by public schools, governmental agencies, advocate groups, and others. MDP staff then followed through with eligibility determination activities.

Chart 1 portrays the referral process up to the point of actual diagnostic services.

Chart 2 illustrates the process once a client is determined to be eligible for evaluation and other services.

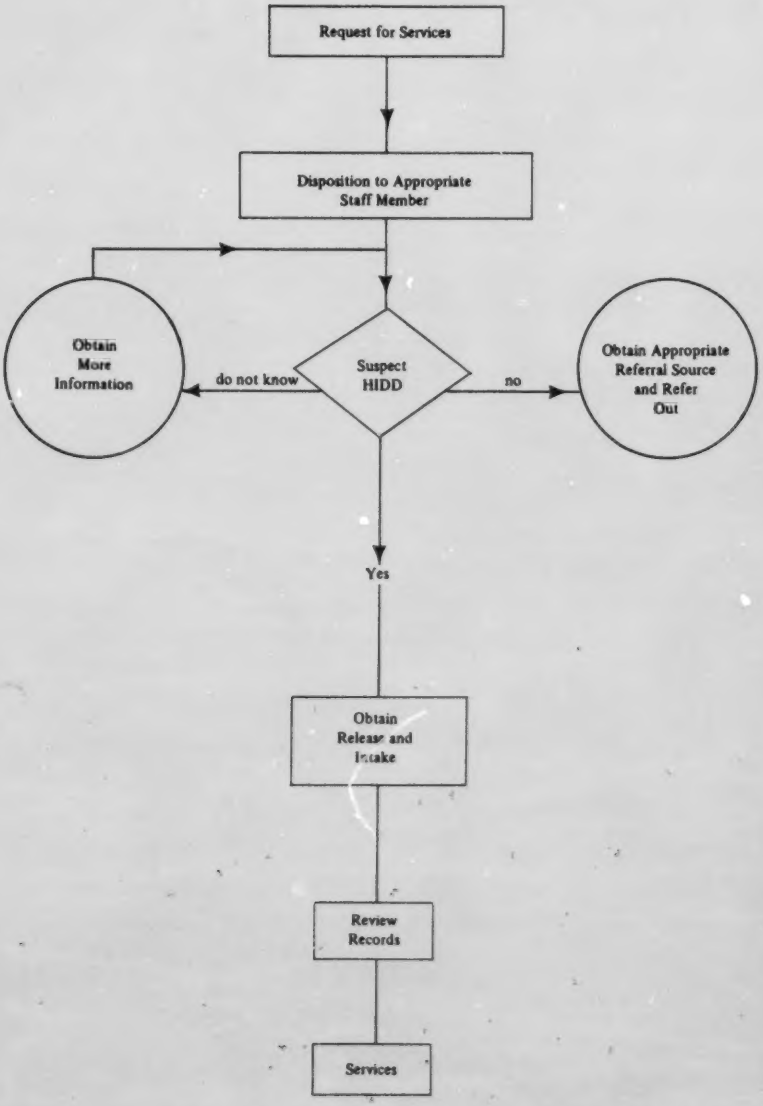
Chart 3 shows the audiological assessment process.

A later section of this chapter describes the mobile evaluation unit.

The Arizona Training Program, Phoenix, utilized it's MDP purchase requisition fees to pay for the services of an audiologist in its study of the contributions of such services in the A.T.P.P. facility. Results are discussed later in this chapter.

CHART 1

THE REFERRAL/INTAKE PROCESS
1976-1978



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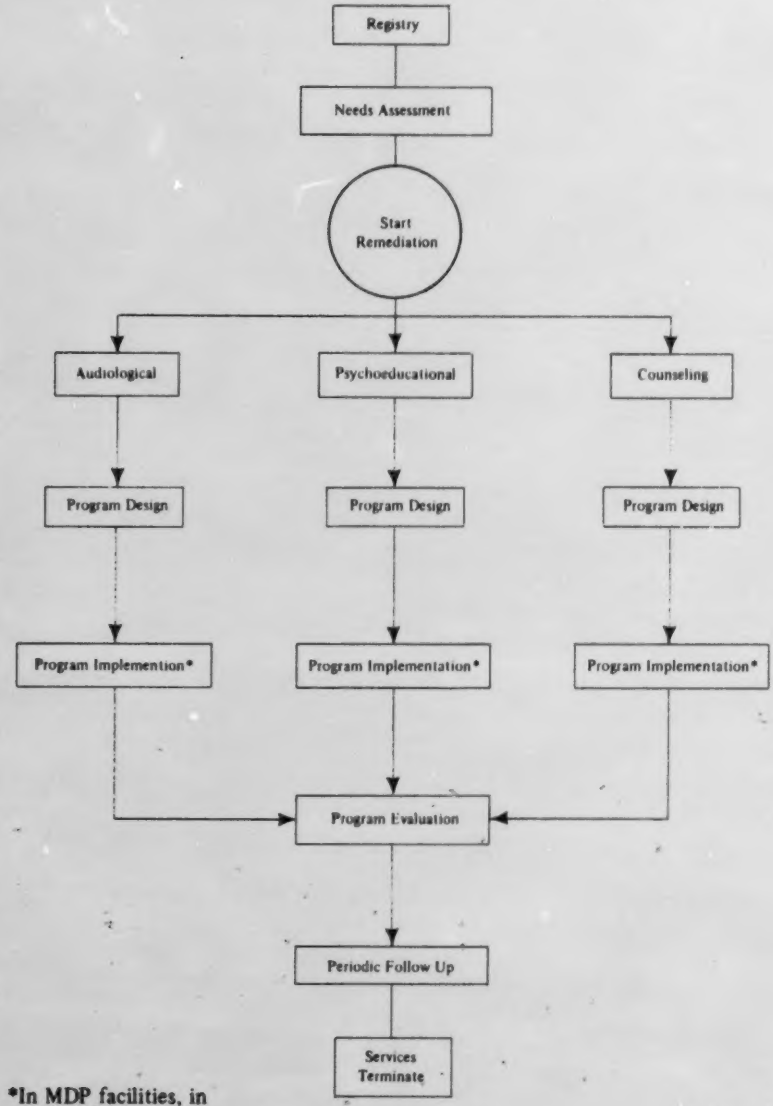
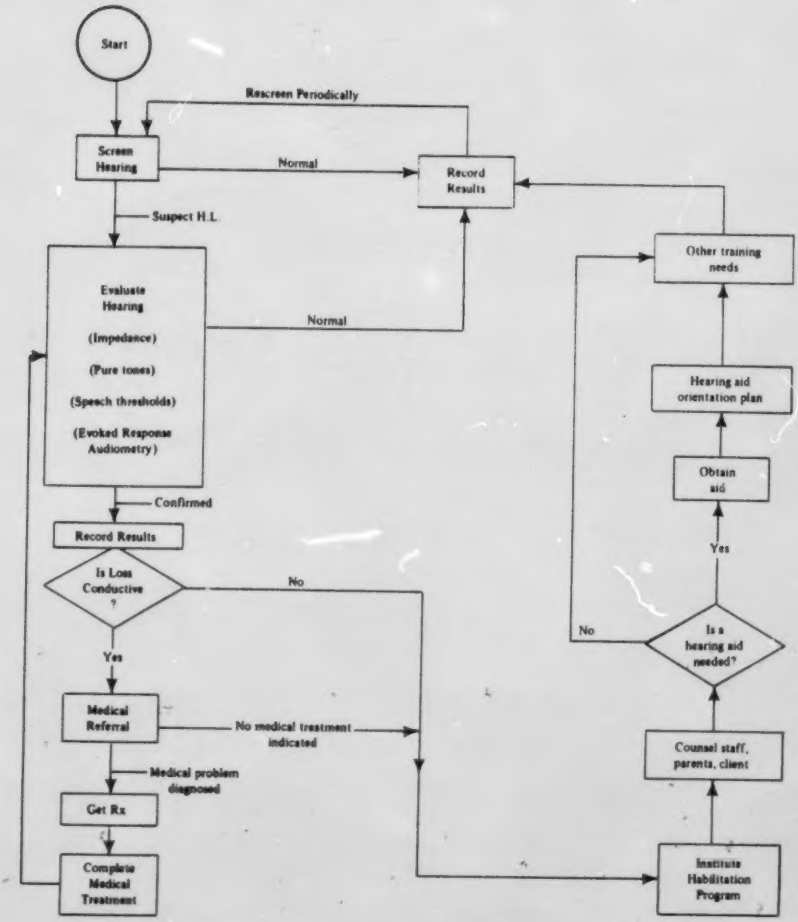
MDP SERVICE PROCESS



*In MDP facilities, in cooperating agency/school, or combined

CHART 3

MDP AUDIOLOGICAL ASSESSMENT PROCESS



In certain cases, hard-to-test HIDD persons were referred by the MDP audiologist to the Speech and Hearing Center, The University of Arizona, for evoked response audiometry testing. This was found to be a critical element with severely to profoundly handicapped HIDD persons who could not respond to standard procedures.

As pointed out in Chapter 5, more than 400 persons were referred for audiological testing from October, 1976 through May, 1978. Later, under the previously cited contract with the Arizona D.D.D. – M.R. Services, a total of 286 additional persons received audiological evaluations.

The audiological services provided at A.T.P. – Phoenix resulted in a large number of units of services for HIDD persons, including 94 hearing evaulations for A.T.P.P. clients, 354 community client evaluations, and 97 medical referrals during the period April 01, 1979 through June 30, 1979.

Cumulatively, then, MDP-sponsored audiological services reached a total of more than 1,231 developmentally disabled individuals in Arizona. A letter dated July 25, 1979, from A.T.P.P.'s coordinator of communication services, summarizes the value of these audiological services:

> It has been a rewarding program. With your [MDP] assistance and [the audiologist's] expertise we were able to identify and evaluate all the clients in our district who needed attention for hearing related problems. We were able to recommend medical attention where needed, IPP objectives developed by our audiologist and staff and provide staff training and consultation to our own institution and community programs.
>
> Joan P. Lowell

Audiological and hearing aid considerations with HIDD persons are discussed in related publications by MDP staff [Rochlin, G.: *Normal auditory development*, 1978; *Audiological testing and terminology*, 1978; *How to help a person who is hearing impaired and developmentally disabled benefit from a hearing aid* (1978); *Audiology with hearing impaired developmentally disabled persons: an annotated bibliography* (1978)].

The Mobile Audiological/Educational Assessment Unit

The mobile unit is built on a 1977 Chevrolet C-65 series truck chassis with a separate cab. A 366 C.I.D. engine supplies power to the tandem rear wheels through a 5-speed transmission and 2-speed rear axle. The cab is air-conditioned and the cab floor is carpeted to absorb vibrations. Power steering and vacuum-assisted brakes make for easy handling of the 23,000 pound vehicle. The overall height from the ground is 12 feet, and from bumper to bumper the unit measures 35 feet.

A six-step fold-away stairway on the right side of the vehicle provides entry to the work area. Situated just inside the door is a waiting room where teachers and parents may sit with the person to be tested and help him/her to become familiar with the new and unusual environment. An adjacent washroom is equipped with a fresh water sink and chemical toilet.

The audiological testing area to the rear of the waiting room consists of an Industrial Acoustics Company sound attenuated room with a table, chairs and various headsets and speakers. The adjacent soundproofed control room is fully equipped and has an observation window to the sound room. The total area represents a virtually noise-free environment in which an audiologist may perform pure tone, speech, sound field, and impedence audiometric evaluations.

To the front of the waiting area, another separate room with a desk, chairs, and storage cabinets provides an area for conducting diagnostic psychoeducational assessments. A one-way mirror is mounted in the door for observation purposes. The room may also be utilized for interviewing and counseling.

Room temperature is controlled for year-round comfort by a Bard 36,000 BTU A/C-heat pump. Electricity for lights, equipment and air conditioning is drawn from a local 220 volt power source via a 50' long, heavy duty power cord. A built-in Sola Constant Voltage Transformer safely regulates 110 volt power to lights and audio equipment, and 220 volt power to the air conditioner. This type of power supply to operate the equipment on the vehicle was chosen over a fixed generator because of the noise and vibration accompanying such a generator.

All doors in the unit are 32" wide to accommodate persons in wheelchairs and there is available a portable aluminum ramp with a 15° incline which may be affixed to the side of the van to provide for easy wheelchair access.

Compartments for housing the wheelchair ramp, electric cable and transformer, water suppy, luggage, and extra equipment are conveniently accessed from outside the vehicle.

The mobile evaluation unit was an efficient and successful component of the program. Practical experience with the vehicle led the staff to the following conclusions that should be considered by agencies investigating potential mobile evaluation units:

1. The extensive travel time that the driver spends in the cab suggests that money should be invested in the design of the cab compartment. The seats should be as comfortable as possible and a radio should be included to reduce driver fatigue.

2. The Model Demonstration Program's unit is 35 feet long and 12 feet high with a box-like design. Wind resistance, in conjunction with the 23,000 lb. weight of the vehicle, makes gas mileage less efficient than if an airflow design were used.

Also, for a person inexperienced in driving and handling a vehicle of this size, parking and manuevering in a confined area can be most difficult. This means that the audiologist must be a competent driver, or a driver must be hired.

3. The wheelchair ramp, which is efficient once assembled, is awkward to set up and usually requires the efforts of two people.

4. The electrical hook-up is a 220 volt single phase unit with a heavy four-pronged extension cord. While several adaptors are available, a basic knowledge of electricity is required to connect to some local power supply points.

5. The air conditioning/heating system is specially modified to operate very quietly in the sound control rooms. However, with the air conditioning power unit located to the front of the vehicle, just outside the psychoeducational testing room, and the return air vent placed inside the room, the noise and wind levels in that room make the testing environment much less than desirable.

Such interior and exterior design features as well as ease of assembly and hook-up should be given a great deal of consideration by agencies planning to design a mobile vehicle.

Chart, on following page, presents a diagram with dimensions of the unit.

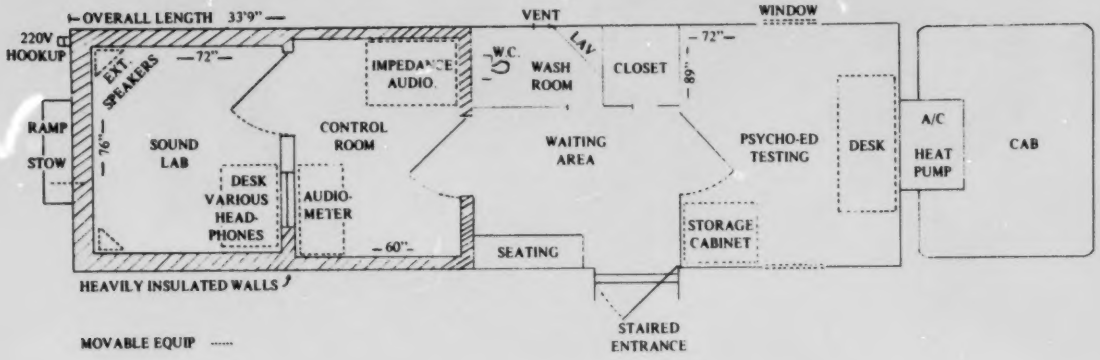
The viability of mobile programs as one solution to the service problems of low incidence populations in rural areas was validated by the experience of the Model Demonstration Program. Access to transportation, financial concerns, scheduling, weather – these and numerous other variables suggest the practicality of bringing services to the handicapped person. At present, various health, library, and recreational programs are operated through mobile systems employing a wide array of vehicle types. The current success of the Mobile Evaluation Unit of the Model Demonstration Program adds one more element to this continuum. With minor modification in design, the MDP's unit and/or similar units can fill a wide gap in the services currently available nationally to persons who are hearing impaired and developmentally disabled.

Educational Assessment, Consultation

As with audiological assessment, MDP services in the area of educational assessment and consultation were offered on a statewide basis. This program component was also announced to schools and agencies via letters, brochures, and conferences. Over the course of the project it proved to be quite heavily in demand, particularly among public school classes for exceptional children.

Table 3 presents a breakdown of child referrals to the Model Demonstration Program over the period November, 1976, to January, 1978, a total of 14 months. The major services requested for the 210 children (ranging in age from 2 years to 21

CHART 4 – MDP MOBILE EVALUATION UNIT



INTERIOR DIMENSIONS

	L	W	H
Sound Room	72"	76"	78"
Control Room	60"	87½"	86½"
Waiting Room	71½"	59"	86"
Toilet Area	48"	30"	86"
Closet	23"	30"	86"
Testing Room	72"	89"	86"
Overall Inside Length	23'10"		

OUTSIDE DIMENSIONS

	L	W	H
Bumper to Bumper	33'9½"		
Length of Box	25'8½"	8"	8"
Outside Width		8"	
Overall Height from Ground			12'
Luggage Compartment	46"	24"	25"
Elec. Cord Storage & Refuse Tank	46"	24"	25"
Water Tank & Heater Compartment	46"	24"	25"
Ramp (3 pieces)	72"	42"	
Weight	22, 490 lbs.		
Doors		32"	(accommodate wheelchair)

years) were audiological assessment and educational assessment, with consultation on program development also in heavy demand.

As can be seen from Table 3, the overwhelming majority of the 210 children served during the 11/76 – 1/78 period were referred to the MDP by schools for the deaf (66, or 31%) and state facilities for the mentally retarded (83, or 39%).

TABLE 3

HIDD child referrals to the Model Demonstration Program 11/76 to 1/78

Source of Referral	Number of Referrals
Arizona Training Program, Coolidge	37
Arizona Training Program, Phoenix	1
Arizona Training Program, Tucson	44
Arizona Bureau of Mental Retardation	1
Public Schools in Arizona	38
Arizona State School for the Deaf and the Blind	27
Center for Hearing Impaired Children (CHIC)	1
Arizona Diagnostic, Treatment, and Education Center (ADTEC)	18
Phoenix Day School for the Deaf (ASDB)	24
Bureau of Indian Affairs (Federal program)	4
Center for Exceptional Children (State)	1
Vocational Rehabilitation	1
Parent, other	13
Total Referrals	210*

*Males 130, females 80; age range 2-21 years

Public schools and parents were also greatly involved in making referrals to the Model Demonstration program. Together, these referral sources accounted for almost 25% of all referrals. These sources made heavy use of educational assessment and consultation on an on-going (as opposed to "one-time") basis.

The methods and techniques used by the project's education consultant are discussed in another publication (Palm and Perine, in press). However, here it is germain to point out that the MDP teacher consultant was called upon to perform a critical, basic function in the education of the handicapped (i.e., educational diagnosis), and the demand for this basic function was greatest in public school classes for exceptional children. The fact that so many schools and agencies requested this fundamental service suggests that a regional program such as the MDP within each state could fill an important role on a continuing basis.

Publications produced by the MDP to assist in education programming with HIDD persons included:

Cober-Ostby, C. *Communicating with HI/DD persons* (1979).

Palm, V. *Annotated bibliography of resource materials for use in teaching the HIDD person* (1978).

Palm, V., Perine, J. *The individualized learning system* (I.L.S.) (in preparation).

Counseling, Parent Education, Advocacy

A third major component of the MDP array of direct services consisted of counseling assistance for HIDD persons and their families, parent education activities, and advocacy. The latter activity included assisting HIDD persons to obtain services from other agencies, encouraging special HIDD program development by schools and agencies, and, in some cases, obtaining legal protection for HIDD children and adults who were being abused or neglected.

These services were offered on a statewide basis, and were evenly divided among children and adults.

During the first project year, the project counselors (2) divided their efforts between developing supportive systems within the community for HIDD persons – such as helping health, education, and welfare agencies to become more responsive to and aware of HIDD persons and how to help them – and (a) serving as a resource to MDP staff who were working directly with audiological and educational client referrals, and (b) establishing parent education and sibling education groups in conjunction with the ADTEC and Tucson Unified School District programs for the severely handicapped. The training of foster home "parents" was another vital counseling function as were casefinding and referral activities.

All of the above cited counselor activities were basic to the success of the MDP services program since they resulted in creating the supportive systems that are so crucial in assisting the HIDD individual who is largely limited in the area of independent functioning.

These activities and others in the area of community living, job training, and employment (both independent and sheltered) were carried out during the second project year. Counselors were also active in conducting workshops and training sessions for a variety of professionals.

Publications resulting from the counseling component include:

Cober-Ostby, C. *Family Support Programs* (1979).

Cober-Ostby, C. *HIDD Fact Sheet: Counselors in Training* (1979).

Cober-Ostby, C. *Counseling Families of HIDD persons* (1979).

Cober-Ostby, C. *Counseling Services for the HIDD* (1979).

Cober-Ostby, C. *Vocational Programming for the HIDD* (1979).

Sheltered Residential Living/Training

A basic problem in the deinstitutionalization of the developmentally disabled is the widespread *lack* of properly supervised residence facilities within the community. This problem is especially pronounced with HIDD persons, since they are often unable to benefit even when there are such facilities due to the fact that residence unit staff are unprepared to communicate effectively with them. While the HIDD person may *exist* in a sheltered residence or independent living training unit in the community, he or she will generally profit minimally from the experience unless the ever-present communication problem is resolved through staff expertise in the use of visually-oriented communication methods and techniques such as a sign language, pantomime, role playing, and systematic gestures. Recent experience across the country has demonstrated that even non-hearing impaired persons who are developmentally disabled benefit from non-oral communication methods/techniques when serious expressive or receptive language skills are impaired.

In Arizona, unfortunately, there were few sheltered residential units in operation for the developmentally disabled during the life of the Model Demonstration Program. The deinstitutionalization concept was just beginning to take hold in the state in 1976, and consequently there were few of these group residential facilities. No special provisions of any kind were in effect for HIDD persons in any of the existing community facilities.

From the outset, the Model Demonstration Program staff recognized the critical place of the community-based group residence/independent living training facility. Initial plans were made to assist on-going, general facilities for the deaf or the developmentally disabled to strengthen their programs for the benefit of HIDD persons. When it became apparent that there were few facilities for this purpose, the project concentrated on assisting one particular agency for the deaf (the Community Outreach Program for the Deaf, in Tucson) to establish a small group home/independent living facility for deaf/severely handicapped adults. This help was in the form of partial funding via purchase of client services, technical assistance, and consultation. The C.O.P.D. program served eight (8) clients at one time, four of whom were HIDD adults.

The experience with the C.O.P.D. group residence facility was a highly positive one. The four initially enrolled HIDD individuals successfully completed the program and went on to independent living and employment in the community.

The presence of knowledgeable and skilled staff was found to be critical. Sign language was used by all staff – some of whom were themselves deaf - and the peer interaction permitted by the use of a common language (sign language) was considered invaluable in fostering social interaction skills as well as the learning of independent living skills.

The communication methods issued is usually of minor importance with HIDD persons who have *only* a mild hearing loss and no major language deficits. For those who have a serious hearing loss, or important language deficits, communication methods assume *central* importance. Whenever a client cannot communicate with peers or staff, learning is minimal if it takes place at all. Appendix 12 contains the evaluation process content and general structure of the C.O.P.D. group home program along with a job description for supervisors or "houseparents".

The MDP staff soon recognized that the C.O.P.D. residential/independent living unit, with maximum enrollment eight (8) persons was not large enough to serve a significant number of HIDD persons. In view of the large numbers of HIDD persons in state institutions, and the project's need to demonstrate effective models for HIDD persons in the deinstitutionalization process, the project decided to seek means for establishing more community living facilities for them.

Initially, the Arizona Bureau of Mental Retardation was approached with the proposal that a joint (B.M.R./MDP) effort be undertaken to fund, establish, and operate a group home/independent living training facility for HIDD persons. The B.M.R. response was in opposition to the proposal on two grounds:

(1) B.M.R. philosophy at the time was strongly in the direction of "mainstreaming" the handicapped in all phases of services. To separate HIDD persons in a special group home would run contrary to this philosophy.

(2) B.M.R. was already planning community units for the developmentally disabled, and HIDD persons would be assimiliated in a normal fashion in these units rather than be grouped in one specific unit. To fund and operate a special HIDD unit did not merge with B.M.R. plans.

Disagreeing with the B.M.R. mainstreaming stance where it related to seriously hearing impaired persons, but not in a position to do anything else, the M.D.P. waited one year for the above item, number (2), to materialize, at which time the project staff would assist in training B.M.R. group home staff to work with HIDD persons. After the year had passed, with continued planning but no new group homes, the project reapproached B.M.R. with the proposal that a modular unit being planned for MDP demonstration applications be used as a group home/independent living training unit for HIDD persons. This proposal was made partly because project time was running out and the project director was concerned that the project would eventually end without anything substantial accomplished in demonstrating model concepts in the area of community living with HIDD persons.

However, once again opposition to the proposal was presented, and again for the same reasons. At the time, however, B.M.R.'s response was more strongly in the direction of having special communications training for all staff who would be working with HIDD persons once the B.M.R. group homes were established.

Another year, the third project year, passed without implemention of the group home/independent living concept for HIDD persons. As this report is written, no program was in operation for HIDD persons in the community residence/independent living training area except for the C.O.P.D. Group Home. The latter continues to serve a vital role in the deinstitutionalization process for HIDD adults. The C.O.P.D. experience, however, clearly demonstrated the important role of the specialized group home/independent living training facility in the deinstitutionalization and rehabilitiation of HIDD persons. Other integrated models, such as proposed by B.M.R., will undoubtedly prove to be equally important for many HIDD persons whose hearing loss and/or communication skills impairment are minimal. Such integrated models should be viable *if* the staff and residents use total communication. However, if the communication problem for HIDD persons is not resolved within any given group residence where there are HIDD persons, the latter's learning and adjustment will be unfortunately and needlessly restricted.

Specialized Educational Facility

Another component of the MDP was its educational program for HIDD children of preschool and school age. This program was implemented initially through placement of a major component - staffed by 3 teachers and 8 aides - within the Arizona Diagnostic Treatment and Education Center (ADTEC), a division for sensory impaired, multiply disabled children within The Arizona State School for the Deaf and the Blind in Tucson. The ADTEC educational system, as discussed in Chapter 2, utilized a special diagnostic/prescriptive educational system especially designed for the multiply handicapped sensory impaired (deaf, blind), and the MDP wished to demonstrate the efficacy of this ADTEC system with HIDD children.

Cooperative arrangements were also sought with the Adaptive Education department of the Tucson Unified School District (TUSD) and with the Arizona Training Program in Coolidge (ATPC). Together, the ADTEC, TUSD, and ATPC programs would permit the MDP to study, describe, and disseminate information on three distinct models of services to HIDD children - the specialized diagnostic center model (ADTEC), the special education/public school model (TUSD), and the state residential facility model (ATPC).

The state residential facility model of HIDD persons is described in a publication by Stewart, Overbeck and Miller (1978). The other models are described in a publication by Palm and Perine (now in preparation, August, 1979).

The MDP was unable to *verify* the applicability of the ADTEC model with HIDD children. Many complex administrative and philosophical problems interferred with

the effective implementation of the cooperative study by MDP/ADTEC. One of these problems, but only one of them, was that the ADTEC model was found to continue to be in its developmental and theoretical stages, not yet fully operational. When this finding emerged - and, in another area, the planned temporary (modular) classroom to be built by the project at ADTEC was being delayed by problems with the contractor and compounded the crowded conditions at ADTEC facilities - the demonstration component at ADTEC was moved to the MDP facility. With this change, the MDP operated its own educational component, which was considered to be a demonstration of a new innovative center located where deinstitutionalization should begin - within a state residential facility (Arizona Training Program, Tucson). The MDP educational program, despite being located at ATPT, was different from the Coolidge (ATPC) unit in that the former was operated independently of ATPT and hence was comparable to ADTEC in its "free standing" structure.

The MDP educational model for HIDD children is described in Palm and Perine (in preparation, August 1979).

The educational models described above are conceptualized structurally in Chart 5 on the next page.

The MDP educational model was staffed by 3 teachers and 3 aides, with classes for preschool children, elementary school age children, and adolescent children. A total of 9 HIDD children were enrolled during the one year of its operation. Support staff consisted of an audiologist, a counselor, a unit supervisor, a media development specialist, and a driver. Research and training personnel assisted as needed.

The children served by the MDP model later were successfully returned to their local schools, with assistance in programming and ongoing support services provided by MDP staff on an itinerant basis.

Coordination of Services

A major goal of the MDP was to impact upon the coordination of services for HIDD children and adults. The poor quality of such coordination throughout the nation is discussed in Healey (1975), and was verified by the needs assessment conducted in Arizona by the project in January, 1977 (Stewart, 1977).

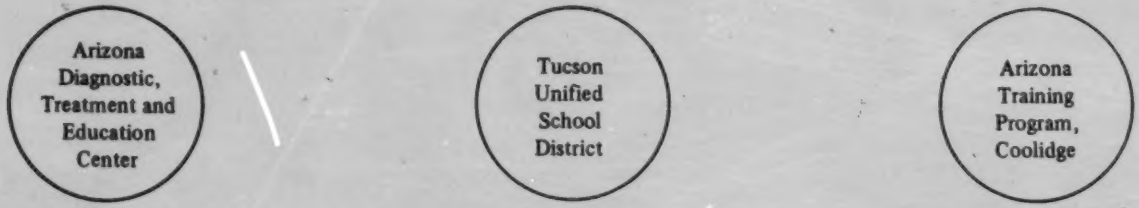
The MDP approach to improving coordination of services was five-fold:

1. Meetings were held with school and agency service coordinators to discuss the needs and potential solutions. These meetings served to sensitize the participants to the needs of HIDD persons as well as initiate contacts among them.

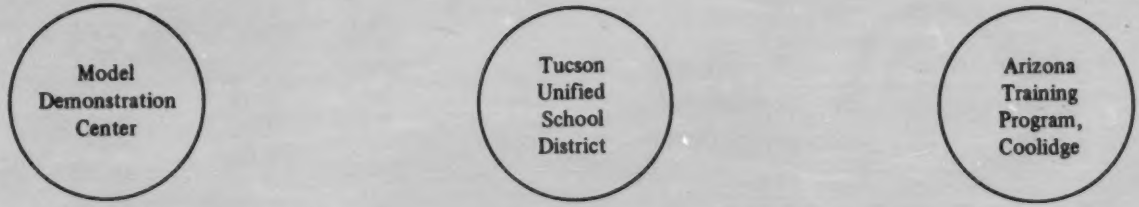
2. Conferences and workshops were held where information about each agency was shared. Often, service workers had only minimal information about other

CHART 5 – EDUCATIONAL MODELS FOR HIDD PERSONS

YEAR I (1976-1977)


Arizona Diagnostic, Treatment and Education Center
Diagnostic Center Model
Tucson Unified School District
Public School Model
Arizona Training Program, Coolidge
State Residential Facility Model

YEAR II (1977-1978)



agencies, hence, these workshops and conferences were quite helpful to workers as they educated one another about their services. Acquiring such knowledge is the first step in fostering better coordination.

3. The project published a directory of services, a newsletter, and other printed information designed to foster improved coordination, and disseminated these to schools and agencies in the state and nationally.

4. MDP staff served as catalytic agents in the referral process, and in their every-day casework they shared information about other agencies/schools with parents and professionals. Again, this laid the ground work for better coordination.

5. The project worked directly with the Governor's office in Arizona in promoting improved coordination. In the process, conferences were held with the administrative heads of the Arizona Department of Economic Security, the State Department and the Arizona Developmental Disabilities Planning and Advocacy Council (A.D.D.P.A.C.)). These conferences resulted in increased awareness of the HIDD population and its needs, and also in support for focused efforts on behalf of HIDD persons.

The project had hoped that schools and agencies would select special workers on their staff to focus upon coordinating their services for HIDD persons, and to a real extent this did indeed come about although the specific agent or change in any given case may not have been these conferences. Rather, the cumulative effects of a variety of activities by the project and by schools and agencies dovetailed to create means for improved coordination. Among these "means" were:

1. The Arizona Division of Developmental Disabilities - Mental Retardation Services (formerly the Bureau of Mental Retardation) established a Task Force on the Sensory Impaired, and, through its activities it is presently coordinating agency planning for HIDD and other sensory impaired developmentally disabled persons.

2. One D.D.D.-M.R. Service District Manager is coordinating planning for HIDD persons statewide in Arizona.

3. The attention focused upon the HIDD population by the Project resulted in specific attempts by A.D.D.P.A.C. and Arizona's CHILD FIND to improve the process of identifying and referring H.I.D.D. persons to appropriate services.

At this time, as the M.D.P. comes to a close, its efforts in the area of fostering improved coordination of services have indeed produced significant results. However, these effects may be only of short term duration. The project's main objective, which was to create a viable, structured coordinating mechanism of a formal nature, was not met due to changing leadership at the state level. The Arizona governorship changed hands three times during the life of the project, and one result of this "turbulence" was continued interruptions of M.D.P. efforts to set up a structured, state-backed coordination system for HIDD persons. The

project staff believes that truly sustained, effective leadership in coordinating services can come about only where there are mandated efforts. Otherwise, the effects of staff turnover, changing priorities, and diffuse agency/school responsibilities will dilute the HIDD focus and result in an abandonment of focus upon HIDD persons.

Prevention, Early Identification

MDP staff efforts in the area of prevention and early identification of HIDD conditions were channeled in the direction of professional training. Publications were produced relating to these topics, which in turn were disseminated to educators, rehabilitation workers, medical personnel, and other workers in the fields of hearing impairment and the developmental disabilities.

The prevention of HIDD conditions is a complex subject that has implications for *all* workers in the entire health, education, and welfare field. As discussed in Chapter 4, the causes of HIDD conditions are many and varied. Prevention calls for efforts of physicians, educators, public health workers, nutritionists, and a host of other workers from various disciplines. To the extent that our nation can effect successful programs in maternal and child health care as well as in infant and preschool level early identification programs, we can expect a substantial reduction in the future incidence of HIDD conditions. No single agency or organization could possibly be responsible for control of the many etiologic agents that lead to hearing impairment and the developmental disabilities. Only massive, longitudual public educational efforts, combined with appropriate maternal and child health care programs in every state and city, will lead to a diminishment of multiple conditions. Until then, early identification through such programs as CHILD FIND and CRIB-o-GRAM will enable us to identify these HIDD children before the results of their conditions handicap them beyond remedy.

The maintenance of high risk registries in every state offers promise in the area of secondary prevention. Legislated programs for the inocculation of women against rubella, before pregnancy, will go far toward erradicating maternal rubella and its effects on thousands of innocent infants. The State of New Jersey has pioneered the way in this particular area; other states should follow.

SUMMARY

This chapter has given a broad overview of the service activities of the Model Demonstration Program. The actual service work of the project was important in giving the project staff experience in attempting to develop a model chain of coordinated services for HIDD children and adults. This experience demonstrated conclusively that our nation is *not* underserving HIDD people simply because of a lack of know-how. The know-how is there. The real problem is that HIDD people are a minority group with few advocates, but with problems that require a lot of

money to solve. Most service/school leaders either are unaware if HIDD persons as a significant population, or they are so involved with other activities that they do not want to, or cannot afford to, focus upon HIDD persons. Up to the present time, neither schools for the deaf *nor* facilities for the developmentally disabled have been willing to assume a leadership role in serving HIDD persons. The picture is changing, however. With the information on the HIDD population and its needs much more clearly defined as a result of the MDP and paralleled events, the future looks brighter. Chapter 7 will attempt to show the way through "models of services" for HIDD persons.

CHAPTER 7

SERVICE MODELS FOR CHILDREN AND ADULTS WITH HEARING IMPAIRMENT AND DEVELOPMENTAL DISABILITIES

Previous chapters have described the Model Demonstration Program, the HIDD population, and the work of the Model Demonstration Program. This chapter will present a discussion of the unique service needs of HIDD persons as identified by the MDP along with the program models appropriate for meeting these needs. An attempt is made to extract the most important information gained about the HIDD population by the project and to relate this to action-oriented diagnostic and treatment services in a variety of settings.

Service Needs

As we have seen, the hearing impaired developmentally disabled (HIDD) population is a relatively large one. It is also a heterogeneous one. For any one category of the developmental disabilities, there are no less than 16 possible combinations of disability in reference to hearing loss. Table 1–illustrates these possible combinations for autism/hearing loss. Parallel combinations are possible

TABLE 1

16 Possible Combinations of Disabilities with Autism and Hearing Loss

Severity of Hearing Loss	Severity of Autism: Mild	Moderate	Severe	Profound
Mild	(1)	(2)	(3)	(4)
Moderate	(5)	(6)	(7)	(8)
Severe	(9)	(10)	(11)	(12)
Profound	(13)	(14)	(15)	(16)

with cerebral palsy, epilepsy, and mental retardation. With 16 possible combinations for each of the four basic multiple disability categories (i.e., hearing loss and mental retardation, etc.), we see that there are 64 possible clear-cut combinations within the HIDD population.

The number of combinations possible where more than two disabilities are involved becomes staggering. We are faced with the fact that indeed a large proportion of HIDD persons also have a third and fourth disability if not even more. It is not uncommon for hearing impaired mentally retarded individuals to have some form of epilepsy, and cerebral palsy is often a fourth disability.

Hence, it is clear that the HIDD population is made up of a wide variety of individuals having a broad, varied range of problems and needs. The complexities involved in understanding and serving the population can be bewildering if not overwhelming unless a meaningful perspective can be developed for viewing the population.

We propose that the factors of *communication ability* and *developmental lags* serve as the focal points in all considerations of the HIDD population and serving its members.

This is not to say that other problems of the population are secondary, far from it. What we are saying is that HIDD people have problems that differ from other developmentally disabled persons because of hearing loss and developmental lags. Hearing loss decreases auditory input from the environment and reduces, if not eliminates, auditory-based communication. The HIDD person is effectively put at a distance, or isolated from, the world of sound. From this comes a wide range of developmental problems and associated educational, social, vocational, and personal needs.

The Problems of HIDD persons

Infants who are born with a hearing loss may be immediately faced with a course of development throughout their lives devoid of meaningful sound.

What are the implications of congenital hearing loss?

- Normal speech and language development are slowed if not practically stopped before a start can be made.
- Normal interpersonal communication within the family circle is limited if not completely precluded.
- Sound-based information from the environment does not reach the mind of the child, or it arrives in a distorted fashion. Warning sounds, familiar sounds, sounds that orient, sounds that help us learn and share, sounds that please and stimulate are absent or only vaguely received.

- Upon arriving at school age, the child may enter first grade with no language patterns, little if any speech, and practically no form of meaningful communication. Many pieces of information the hearing child absorbs from birth until the age of six have not been assimilated by the hearing impaired child, and yet he or she is expected to function and learn along with the hearing child.

- As the congenitally deaf child progresses through school, the gap between potential and achievement continuously widens. The older one becomes, the more important verbal language and verbal communication become. Yet, verbal communication and language are the deaf child's greatest weaknesses.

- The negative impact on subsequent learning and adjustment in adulthood is predictable unless appropriate special education efforts have been instigated at an early age.

These same implications are largely true for the child who becomes hearing impaired before the age of four or five years. This child and the congenitally hearing impaired child—both prelingually deaf—share common problems and needs.

The child who becomes hearing impaired after the age of four or five years (after the establishment of basic language skills and speech patterns) is not usually as severely handicapped as the prelingually deaf child. Yet, other problems are presented when the input of sound is diminished or lost. A tool for survival (hearing) is taken away or weakened. Uncertainty occurs. Established ways of relating to others are disrupted. Speech usually deteriorates with the passing years. New input from the environment is distorted or lost. Functioning in the family, in the neighborhood, at school, and at play is impaired. A handicap is produced that will send echoes through the remainder of the child's life. Future educational growth, postsecondary education, career choices, social opportunities, all are affected.

The young adult is also uniquely affected by the onset and continuation of hearing loss. Although the individual may previously have developed normally within his or her capacitities to do so, the onset of hearing loss initiates a major change in one's world. It is as if a curtain of silence, or a muffler of sorts, were placed between the individual and everything else of an auditory nature.

The same curtain of silence or muffled sound may descend upon the mature or older adult. In each case, a major tool for survival, hearing is taken away or weakened. One's long-standing ways of communicating with the world are suddenly seriously impeded or destroyed. Painful readjustments must be made. One's psychological equilibrium may be thrown off center.

We can easily see that the effects of hearing loss are determined in large part by the type and severity of the loss as well as the age at onset of the loss.

Equally important factors to be considered are the extent and quality of family interaction with the hearing impaired person, early identification and treatment (medical, audiological), and appropriate social/educational/habilitation/rehabilitation services.

- The more family members interact constructively with the hearing impaired person, the better growth and development will be.

- The earlier the loss is identified, the earlier appropriate services and assistance can be rendered.

- The more appropriate the treatment (surgery, family or individual counseling and guidance, fitting with a hearing aid, speech therapy, instruction in sign language, appropriate educational placement, habilitation and/or rehabilitation services) at the earliest possible time, the less will be the impact of the hearing loss on one's development and adjustment.

Hearing loss may affect persons who are developmentally disabled in essentially the same manner that it affects nondevelopmentally disabled individuals, with one very important difference. This difference, simply stated, is that hearing loss in a developmentally disabled person compounds the problems created by the developmental disability or disabilities.

The autistic individual's adjustment is qualitatively affected by hearing loss. We as diagnosticians and treatment personnel often find it difficult to ascertain whether specific behavior is a function of hearing loss or autism, and the already-difficult task of interpersonal communication may become seemingly impossible.

The cerebral palsied individual's development and adjustment are obviously made more complicated by the language, speech, and communication handicaps imposed by hearing loss.

The person who is epileptic may be adversely affected by hearing loss. Emotional frustrations increase as a consequence of many problems created by each of these disabilities. The total impact upon the individual can have devastating effects in personal, social, and vocational areas.

The condition of mental retardation can only be worsened by any additional disability. Hearing loss in particular, because it creates a communication barrier between the person and his/her world, reduces input from the environment and further complicates the mentally retarded person's developmental tasks.

Problems in the Service Area

The problems created by hearing loss, as we have seen, may present severe

disruptions in one's growth and development. Unfortunately these problems, too often, go unheeded or untreated by workers in the human services fields.

- All too often there are minimal attempts at early identification of developmentally disabled persons who have a hearing loss.

- Too few agencies or schools have personnel who are capable of diagnosing hearing loss among the more severely handicapped developmentally disabled population.

- Very few schools and facility programs have treatment/education/habilitation programs geared toward meeting the special needs of developmentally disabled clients/students who are hearing impaired.

- Too many school and agency personnel, lacking a qualitative understanding of deafness, believe that a hearing aid and speech therapy are panaceas for all the problems of HIDD persons.

- Generally, too many program administrators assume the HIDD clients/students are benefiting from various services that "do not seem to require communication."

- Where sign language is used by program personnel, too often their expertise in the actual use of sign language is minimal. Program administrators, not knowing sign language, often assume a level of expertise in their staff that may not exist.

- There are explicit professional standards in the education of the deaf. There are explicit professional standards in the education of developmentally disabled persons. There are no established professional standards whatsoever in the education of hearing impaired developmentally disabled persons.

In this vacuum created by the lack of trained personnel and organized service program efforts, HIDD persons of all ages remain one of the most underserved minorities in the nation.

Service Needs of HIDD Persons

Considering the known problems of children and adults who are hearing impaired and developmentally disabled, what can we identify as their service needs?

The HIDD individual will need a program of specific services, based upon the nature and severity of his or her handicaps. General needs of HIDD persons as a group, however, can also be identified. Each of these general needs may be seen as coming from the communication deficits and development lags associated with hearing loss. This statement, of course, acknowledges that the population also

shares the problems and needs of other developmentally disabled persons. The task becomes one of removing, alleviating, or otherwise compensating for the deficits created by hearing loss within the framework of services for the developmentally disabled.

1. *Early Identification.* All HIDD persons need to be identified as early as possible after the onset of their hearing loss. The earlier the identification, the sooner that help can be made available.

2. *Referral.* HIDD persons and their parents need to be referred for appropriate assistance as soon as possible after identification.

3. *Direct Services.* Appropriate services are needed in a variety of locations and settings. The following listing of services gives an indication of the needed array.

In the state of Arizona (and Arizona is typical of other states in this regard) the Model Demonstration Program identified the following service needs of HIDD persons:

a. Prevention Programs
b. Early Identification
c. Appropriate Diagnosis
d. Proper Placement
e. Proper Instruction and Training
f. Parental Counseling and Guidance
g. Personnel Preparation
h. Sheltered Employment Opportunities
i. Pre-Vocational Training Opportunities
j. Vocational Training Opportunities
k. Group Living Opportunities
l. Independent Living Opportunities
m. Health Care
n. Recreational and Social Participation Opportunities
o. Community Support Services

As we can see, these services do not differ from those typically required for many developmentally disabled persons. Of significance is the fact that the great majority of these services are not readily available to or do not impact upon hearing impaired developmentally disabled persons because of the fact that few provisions are available for dealing with the client or student's communication problems.

The situation amounts to a barrier to the delivery of available services; the barrier is hearing loss.

Many service workers tend to overlook the crucial nature of communication in the learning and adjustment process. They reason, "The service is here. If we expose the HIDD person, he or she will learn."

This view is naive. It is equivalent to offering these services to English-speaking clients through personnel who use a language such as Swahili or classical Sanskrit. Yes, eventually something will "soak in." The question is, "Is this how we want to do it?"

The use of Total Communication is crucial with seriously hearing impaired persons. Total Communication (TC) includes the simultaneous use of spoken language, sign language, gestures, and other visible communication devices and methods as well as auditory amplification when appropriate.

Moreover, an understanding of the nature of communication deficits as well as their impact on the individual is vital to the service worker. This knowledge enables the worker to concentrate service efforts upon activities that offer the most promise to HIDD individuals.

Through TC and proper understanding of the client's problems and needs, services in a variety of settings can sucessfully be provided to HIDD individuals.

Unfortunately, extremely few of Arizona's or the nation's service and education workers are well-versed regarding HIDD conditions and possess skill in the use of Total Communication.

Thus, "available" services are seldom actually available to many HIDD children and adults. Such clients are frequently not even diagnosed as such since many of them represent a hard-to-test group. In such cases, it becomes difficult to even imagine their receiving proper referral, let alone services.

Some HIDD persons can be effectively served by general community agencies and schools; as pointed out above, such agencies and schools need personnel who understand the problems and needs of this population and have the expertise necessary to meet these needs.

Some HIDD persons, because of the severity of their problems, cannot be served by most community agencies and schools. They need specialized assistance, perhaps within a regular school and agency, that can only be given by personnel highly trained to work with this population.

Some HIDD persons can only be served appropriately in a facility program designed for the developmentally disabled population and having program components designed specifically for meeting the needs created by hearing impairment.

Table 2 lists the types of hearing loss and their educational implications.
Table 3 lists the categories of mental retardation and some of their educational implications.

Combining the information from the two tables suggests inplications for hearing impaired persons who are mentally retarded. (Tables 4, 5, and 6).

TABLE 2
HEARING LEVELS FOR SPEECH AND EDUCATIONAL RECOMMENDATIONS

Class	Hearing Level for Speech	Educational Recommendation
1	*30 dB or better.* These children may have difficulty in hearing faint or distant speech but are likely to "get along" in school and to have normal speech.	Children should be given the benefit of favorable seating in regular classrooms and may be assisted by special instruction in speechreading.
2	*30-55 dB* These children usually understand conversational speech at a distance of 3 to 5 feet without great difficulty. They may have some defects in the articulation of their own speech, and they may have difficulty in hearing adequately in school if the talker's voice is faint or if his face is not visible to them.	Children should wear hearing aids and be given training in their use. They should be taught speechreading and also be given the benefit of speech correction and conservation of speech. They should also have the advantage of favorable seating in classrooms.
3	*55-70 dB* These children understand conversational speech only if it is loud, and they have considerable difficulty in group and classroom discussions. Their language and especially their vocabularies may be limited, and abnormalities of articulation and voice production are obvious.	Hearing aids and auditory training, special training in speech, and special language work are all essential. With such assistance and with favorable seating, some children can continue in regular classes. Others may derive more benefit from special classes.
4	*70-90 dB* These children may hear the sound of a loud voice about one foot from the ear, and they may identify some environmental noises and may distinguish vowels, but even with hearing aids they have difficulty with consonants. The quality of their voices is not entirely normal, and they must be taught both speech and language. Many, but not all, children in this class should be considered "deaf" for educational purposes until or unless the combination of an adequate hearing aid and sufficient auditory training makes them only "hard of hearing."	Children should be taught by means of educational procedures for the deaf child, with special emphasis on speech, on auditory training, and on language. After a period of such instruction it is possible that these children may enter classes in regular schools.
5	*90 dB or worse* These children are deaf, even though they may hear some very loud sounds. They never can rely on the auditory channel as a primary avenue of communication. Their speech and their language must both be developed through careful and extensive training.	These children require special educational procedures described in this chapter. Some of them, however, eventually enter high schools for the hearing.

(Davis & Silverman, 1977, p. 436)

TABLE 3

LEVELS OF MENTAL RETARDATION
AND THEIR EDUCATION IMPLICATIONS

Mental Retardation Level	Program Needed
1. Mild	Usually can function adequately in most general programs in public schools with resource help.
2. Moderate	Usually can function well in public school with special instruction.
3. Severe	Can sometimes function in public school special programs; often need individualized training (beyond group instruction). Sometimes require special facility placement for training purposes.
4. Profound	Usually require special training and care. Some are well served in the community. Individualized attention needed.

These examples provide a paradigm, even if less than a perfect one, for viewing the other developmental disability categories. By viewing the needs of the developmentally disabled along with the needs created by hearing impairment we may arrive at a reasonable approximation of the needs of the hearing impaired developmentally disabled.

Thus, we may expect an ideal array of services for the HIDD population to consist of those services typically provided to the developmentally disabled plus special personnel and educational/training methodology and materials appropriate for dealing with the problems of hearing loss and associated developmental lags.

SERVICE MODELS

There are several distinct service models, or approaches, available to program planners who desire to plan appropriate services for developmentally disabled persons who are also hearing impaired. These models are described in this chapter, and brief, general criteria are presented to serve as guidelines for selecting a particular model.

Introductory Background

Our country's educational and human services systems have traditionally offered a variety of approaches to meeting the developmental and adjustment needs of all

TABLE 4

COMBINING EDUCATIONAL SERVICES FOR THE DEVELOPMENTALLY DISABLED AND FOR THE HEARING IMPAIRED

Service Location	Population	Program Modification
1. Public School Classes (Mainstreaming)	A. Mild D.D. population with mild hearing impairment	A. Appropriate seating B. Possible student use of hearing aid C. Speech therapy D. Orientation of teachers to hearing impairment E. Use of visually oriented media
	B. Mild D.D. population with moderate hearing impairment	A. Modifications similar to those for "Mild" hearing plus B. Use of resource teachers and ancillary professionals C. Use of interpreters, tutors
2. Classes in Schools for the Deaf	A. HIDD persons with mild to moderate D.D. involvement and severe to profound hearing loss	A. Use of hearing aids B. Use of group hearing aids C. Use of sign language D. Special training in language, speech, academic areas
3. Special Classes in Public Schools	A. HIDD persons with moderate to severe HI and D.D. involvement	A. Special instruction B. Use of hearing aids and group hearing aids C. Heavy visual orientation D. Use of sign language as well as speech E. Use of interpreters, tutors
4. Residential Facility	A. Severe to profound D.D. involvement, mild degree of hearing loss	A. Use of hearing aid B. Speech therapy C. Orientation of staff to hearing loss D. Use of visually oriented media
	B. Severe to profound D.D. involvement, moderate hearing loss	A. Use of modifications for moderate degree of loss B. Use of resource staff specializing with HIDD population
	C. Severe to profound D.D. involvement, severe to profound hearing loss	A. Use of hearing aids B. Special staff C. Special grouping for instructional social purposes D. Use of sign language

TABLE 5

COMBINING COMMUNITY RESIDENTIAL SERVICES FOR THE DEVELOPMENTALLY DISABLED AND FOR THE HEARING IMPAIRED

Service Location	Population	Program Modification
1. Residential Housing (Community-based)	A. D.D. individuals who have a mild hearing impairment	A. Orientation of housing staff to hearing impairment B. Client use of hearing aid
	B. D.D. individuals who have a moderate hearing impairment	A. Orientation of staff to hearing impairment B. Client use of hearing aid C. Visual fire alarms D. Resource staff
	C. D.D. individuals who have a severe to profound hearing loss	A. Orientation of staff to hearing impairment B. Client use of hearing aid as appropriate C. Specialized staff to work with clients D. Client-staff use of sign language E. Visual fire alarms F. Specialized instruction G. Placement of deaf clients together where feasible for social interaction, recreation

its citizens, young and old. Initially, our approach was a general one. We had one-room schoolhouses with one teacher for a heterogeneous group of children of varied ages. There were family doctors who took care of everyone, and dealt with all kinds of maladies. We had general stores that provided everthing from buttons to plowshares, medicine, wagons, and meat. Gradually, however, specialization has developed and we are now a nation of specialists and specialties. Yet, we continue to see some trends back toward a generalist point of view in many different fields. Hence, in may areas of life there are options whereby we may select a general type of program activity or benefit, or we may select highly specialized ones. The choice is mediated by real needs, personal preferences, availability, and financial as well as professional trends in a given locality. Political forces also play a role.

Thus it is with hearing impaired developmentally disabled persons. Although comparatively little in the services arena has evolved specifically for HIDD persons,

TABLE 6

COMBINING COMMUNITY COUNSELING AND REFERRAL SERVICES FOR THE DEVELOPMENTALLY DISABLED AND FOR THE HEARING IMPAIRED

Service Location	Population Served	Program Modifications for HIDD Persons
1. Community Counseling Centers	A. General Population	A. Orientation of staff to HIDD persons B. Use of interpreters for deaf D.D. clients
2. Community Counseling Centers for the D.D. population	A. General D.D. Population	A. Orientation of staff to Hidd Persons and resources B. Use of interpreters for HIDD clients or employment of staff skilled in sign language
3. Community Counseling Centers for the Deaf	A. General hearing impaired population	A. Orientation of staff to HIDD population and resources related to the D.D.

it is clear that there are options available to program planners who wish to initiate a focus upon meeting the needs of this population.

Planners have the following options:

Option I: The Generic Model: Absorb HIDD persons into general human services agencies or public schools, and depend upon the generalist's knowledges and skills to meet student/client needs.

Option II: Semi-Specialized Model A: Provide generalists with special information about the HIDD population, and expect this to be adequate preparation for the generalist to meet the needs of this group.

Option III: Semi-Specialized Model B: Use Option II above, but additionally employ one specialist with HIDD persons to provide "resource information" to both the generalist staff and to the client or student. Such a resource person is often called a coordinator or consultant, and this individual is expected to be able to resolve any special problems encountered by the general staff with HIDD persons.

Option IV: Specialized Model A: Use Option III above plus additionally employ one or more specialist (a sign language teacher, a psychologist, a counselor, or a

special teacher, etc.) to provide "remedial" or "special support" services as a back-up for regular services.

Option V: Specialized Model B: Employ a specialist staff to work exclusively with HIDD persons in a special unit within a general facility or school or agency.

Option VI: Special Facility Model: Employ a specialist staff to work exclusively with HIDD persons in a special facility serving only HIDD persons.

Strengths and Weaknesses of Options

Each option or model has its advantages and disadvantages, its benefits and its shortcomings, its adherents and its opponents. It is unfortunate but true that all too often the actual model selected in a given state or city is more a function of agency personalities and personal priorities than of deliberate, carefully thought-out analysis and planning. The analysis offered below is an attempt to illustrate a rational analysis of each model's strengths and weaknesses. This information has potential value for agency planners.

Generic Model (Option I)

Strengths: The generic model requires no *extra* funding, personnel, or organizational adaptations.

Weaknesses: Does not permit real focus upon special needs or the delivery of expert, specialized service approaches.

Semi-Specialized Model A (Option II)

Strengths: Same as Generic Model, but adds a degree of special knowledge and skill to worker qualifications.

Weaknesses: Same as Generic Model, and further encourages stereotyping unless training offers specific caveats.

Semi-Specialized Model B (Option III)

Strengths: Similar to Semi-Specialized Model A, but increases worker knowledges and skills through consultation.

Weaknesses: Similar to Generic Model, but not as great.

Specialized Model A (Option IV)

Strengths: Provides generic benefits plus specialized benefits.

Weaknesses: Resource assistance may be inadequate for the more severely handicapped, who may require extensive, intensive services over a long period of time.

Specialized Model B (Option V)

Strengths: Offers generic benefits along with the benefits of specialized, extensive and intensive services.

Weaknesses: Conflict may occur between the generic staff and the specialized staff over space, funds, scheduling, rules and regulations, staff salaries, philosophy, service approaches, program organization.

Special Facility Model (Option VI)

Strengths: Highly specialized services can be offered to students or clients on an extensive, intensive, long-term basis. Removes bureaucratic conflict with generic staff.

Weaknesses: This model requires a very high initial cost for facilities and staff; reduces opportunities for client/student interaction with other people in social settings (unless programming includes opportunities for same); requires recruitment of special staff.

The Generic Model (Option I) can truly "work" (i.e., be effective) only with the very mildly impaired HIDD client or student. The Semi-Specialized Models A and B offer benefits primarily with the mildly impaired. The Specialized Models A and B offer substantial benefits to HIDD clients/students, and the Special Facility Model (Option VI) offers extensive benefits in special areas (e.g., education, vocational training, residential living, etc.).

Adocates and program planners ought to bear in mind that any one state can expect to have a variety of schools and agencies serving HIDD clients, with these schools and agencies offering a mixture of "models." Hence, long-range planning will recognize the desirability of fostering a chain of varied service options rather than one single option in one single location.

COORDINATION – A PROBLEM AND A CHALLENGE

A persistent, nagging problem in the delivery of human services is that of poor or mediocre coordination of services. We all know of myriad instances of duplication of effort, of clients being "dropped between the cracks" in the identification and referral process, and of frustrating delays as the client moves "between" agencies. Indeed, the Rand Corporation, and the General Services Administration (GSA) of the federal government, have identified "poor coordination of available services" as THE major barrier to the effective delivery of human services. This problem appears to be especially severe with the mentally ill and the developmentally disabled who, because of the seriousness of their needs, often cannot effectively advocate for their own rights to get through the red tapes so frequently associated with applying for assistance.

This problem of inadequate coordination of services is especially severe for HIDD clients/students, and in fact poor coordination of services for this group may be viewed as the epitome of agency service coordination problems in the U.S. Although, by law, both services for the deaf and services for the developmentally disabled should be available to HIDD persons, it is far too often the case that each service group assumes the other group is the major source for this population. That this assumption exists partially reflects the fact of poor coordination of efforts, for if these schools and agencies truly communicated and coordinated their efforts they would know their present assumptions are invalid.

The Problem

There are two basic types of coordination in the human services area. One is interagency coordination, and the other is intra-agency coordination.

1. *Interagency Coordination.* In this type of coordination, means and processes of interaction between two or more agencies are effected to facilitate the delivery of appropriate and timely client/student services by each agency.

When these means and processes are not specificied and monitored, coordination becomes incoordination. The resources of each agency are weakened due to delays, conflicts, omissions, and untimely commissions. The client/student "bounces from pillar to post," waiting, often in vain, for the appropriate services at the appropriate time.

2. *Intra-agency Coordination.* Even small, two- or three-person agencies may fall victim to problems with coordination. Incorrect assumptions may be made about the who, what, when, how, and where of client services. Poor communication, inexperience, lack of knowledge, and the absence of planning may foster incoordination whenever as few as two people work together. This being the case, the likelihood of poor coordination increases with the number of personnel involved and the complexity of the task. Hence, poor coordination occurs not only between agencies but within agencies. And, the larger the agency the greater is the possibility for intra-agency incoordination.

Again, only deliberate planning and clearcut lines of responsibility, coupled with careful monitoring of results, can eliminate the inefficiency and even active harm that stems from poorly coordinated service delivery efforts.

The Challenge

The coordination of services for HIDD persons requires placement of responsibility for services at all levels, local, countywide, statewide. Accountability must be defined and monitored.

The question of "who insures coordination" on behalf of HIDD persons within given service systems (education, rehabilitation, etc.) represents the basic issue here. Unless this question is answered, coordination will not occur.

Several mechanisms are available to foster coordination of efforts on behalf of HIDD persons.

1. *Interagency Coordinating Council.* A special statewide committee may be established by concerned schools and agencies for the specific purpose of fostering communication, client/student referrals, and exchange of information as well as long-range planning activities. One individual from each concerned agency can serve as a member of the committee. Typical agencies/schools to be represented on this committee might be:

- School(s) for the hearing impaired
- School(s) for the developmentally disabled
- Community agencies serving the hearing impaired, the developmentally disabled, or both groups
- Vocational rehabilitation agencies
- Post secondary educational facilities serving hearing impaired and/or developmentally disabled people
- Health planning agencies
- The State Department of Education
- The State Developmental Disabilities Department
- The State D.D. Council

A monthly or bimonthly meeting of such a statewide council can do a great deal to foster effective interagency coordination and cooperation.

2. *Statewide Coordination of Services for HIDD Persons.* A second potentially effective mechanism for fostering improved interagency coordination of services is the appointment of one individual to serve as a "Statewide Coordinator of Services for HIDD Persons." Although such a person would be limited in terms of authority due to his/her placement within one department of state services, his/her advocacy efforts need not be stifled.

The coordinator position might be located within a super agency and be one duty of a present staff member or be the single role of a new or existing staff member.

This approach would permit an ongoing effort on a broad scale on behalf of HIDD persons, and would counter trends that result in small minority groups being overlooked for lack of ongoing advocacy.

3. *State D.D. Council Subcommittee.* A third, useful option available to the states is for the State D.D. Council to establish a subcommittee from among its members, charging the subcommittee with the task of maintaining up-to-date information on services for HIDD persons. The resulting information could be periodically shared with service providers via a newsletter. Also, subcommittee meetings could be held with appropriate agency representatives invited to attend and give presentations. This process would do much to foster greater coordination.

4. *Other Options.* No state is exactly like any other state in terms of agency organization, personnel, funding availablity, interest, and political dynamics. The three options described above do not exhaust available concepts for improving coordinating efforts on behalf of HIDD persons. New, unique approaches are encouraged and should be sought, ranging from advocacy groups to citizen's information centers. The actual delivery of timely, appropriate services to HIDD persons is the goal; the "How" of achieving this goal must be an individual, state-by-state decision. The decision, however, is overdue; action is needed now.

Intra-agency coordination involves issues and problems similar to those discussed for interagency coordination. Committees and coordinators are encouraged within agencies to bridge the gap that so often develops between and among other departments within one agency.

SUMMARY

This chapter has attempted to present several basic models that can be used in organizing services for HIDD children and adults. The selection of a specific model by a given agency or school should be based upon student/client needs and local resources as identified through careful analysis. Chapter 8 presents a model for such an analysis.

CHAPTER 8

ANALYZING SERVICES FOR THE HEARING IMPAIRED DEVELOPMENTALLY DISABLED

by

Joseph B. Perine

This chapter presents a model for the analysis of school and agency services for HIDD persons. It is a specific, detailed model. Everyone, practically, will admit that perhaps services for HIDD persons may not be what they should, but few professionals have taken the time to explain how services can be (Chapter 7). Fewer still have attempted to show how gaps in existing services can be identified and improvements effected. In this chapter we will present a model for accomplishing these tasks.

THE ANALYSIS APPROACH

The Model Demonstration Program "Analysis of Services" is basically a transactional evaluation methodology which attempts to assess the relationship among the elements of a human services system. The analysis is designed to evaluate the internal mechanisms of an agency or system in terms of program antecedents, transactions, and outcomes. However, the focus of the methodology is on change and those components of a system which have changed.

During the one full year during which the "Analysis of Services" has been implemented, requests were received from 46 agencies. Each of these organizations was given an evaluation document along with instructions regarding its completion. The list of agencies to which this document was sent is as follows:

	AGENCY	LOCATION
1.	Alabama School for the Deaf & Blind	Talladega, Alabama
2.	American School for the Deaf	W. Hartford, Connecticut
3.	Amoskeag Regional Center – Program for the Hearing Impaired	Manchester, New Hampshire
4.	Austine School	Brattleboro, Vermont
5.	Boston College Campus School	Boston, Massachusetts

6.	Bristol Sheltered Workshop, Inc.	Bristol, Tennessee
7.	California School for the Deaf	Riverside, California
8.	Central State Hospital, Deaf Unit	Indianapolis, Indiana
9.	Child-Parent Center	Tucson, Arizona
10.	Cerebral Palsy Center for the Bay Area	Oakland, California
11.	Crane School District	Yuma, Arizona
12.	Crossroads Rehabilitation Center	Indianapolis, Indiana
13.	Day Classes for the Deaf	Las Vegas, Nevada
14.	Deaf Social Service Agency	Evansville, Indiana
15.	Delaware Curative Workshop	Wilmington, Delaware
16.	Des Moines Area Comm. College	Des Moines, Iowa
17.	Eastern Carolina Sheltered Workshop and Voc. Rehab. Center, Inc.	Greenville, North Carolina
18.	Georgia Center for the Multihandicapped	Atlanta, Georgia
19.	Goodwill Industries of Des Moines, Inc.	Des Moines, Iowa
20.	Goodwill Industries of Battle Creek	Battle Creek, Michigan
21.	Goodwill Industries of Grand Rapids	Grand Rapids, Michigan
22.	Goodwill Industries of Madison	Madison, Wisconsin
23.	Goodwill Industries of Mississippi	Jackson, Mississippi
24.	Human Development Program	Lexington, Kentucky
25.	Illinois Institute for the Developmentally Disabled	Chicago, Illinois
26.	Indiana School for the Deaf	Indianapolis, Indiana

27.	Kansas Elks Training Center for the Handicapped	Wichita, Kansas
28.	Kansas Vocational Rehab. Center	Salina, Kansas
29.	Lehigh Valley Association for Retarded Citizens	Bethlehem, Pennsylvania
30.	Lexington School for the Deaf	Jackson Heights, New York
31.	Madison Opportunity Services	Madison, Wisconsin
32.	Margaret S. Streck School for the Hearing Impaired	Newark, Delaware
33.	Mississippi School for the Deaf	Jackson, Mississippi
34.	Monmouth Vocational Rehabilitation Center	Red Bank, New Jersey
35.	New Jersey Regional Hearing Impaired Center	Wayne, New Jersey
36.	Rehabilitation Programs, Inc.	Poughkeepsie, New York
37.	Seattle Public Schools	Seattle, Washington
38.	South Carolina School for the Deaf and Blind	Spartanburg, South Carolina
39.	St. Paul Public Schools	St. Paul, Minnesota
40.	St. Paul Rehabilitation Center	St. Paul, Minnesota
41.	Tacoma School District 10	Tacoma, Washington
42.	United Cerebral Palsy of Queens, Inc.	Jamaica, New York
43.	Utah Schools for the Deaf and Blind	Ogden, Utah
44.	Virgin Islands Department of Education – Division of Special Education	St. Thomas, U.S. Virgin Islands
45.	Woodhaven School, Inc.	Columbia, Missouri
46.	Wyoming School for the Deaf	Casper, Wyoming

In addition to these specific requests, a number of analyses were mailed to agencies for inspection purposes.

147

RESULTS

Of the 46 agencies receiving the analysis document (The Vital Information Form (VIF)), four returned them with complete information. The agencies were Central State Hospital, Crane School District, Monmouth Vocational Rehabilitation Center, and the St. Paul Rehabilitation Center. Each of these respondents received a detailed analysis of their services, and the St. Paul Rehabilitation Center also participated in an onsite discussion of the results.

Appendix contains the Vital Information Form and related correspondence.

It is unfortunate that so few agencies responded to the VIF, but this was predictable for several reasons. These reasons may be grouped under the categories of 1) the detailed nature of the VIF, 2) the perceived nature of the clientele being served by the agency, and 3) the administrative structure of the service agency. A look will be taken at each of these categories individually in an attempt to assess their effect upon the outcome of the "Analysis of Services."

The Nature of the VIF

The Vital Information Form (VIF) is the heart of the "Analysis of Services" in that it provides the data from which a transactional assessment can be constructed. There are several characteristics of the VIF which may have had a significant effect upon its utilization by requesting agencies. First of all, the VIF is lengthy. It contains three sections totalling 30 pages. All of the required data are descriptive, necessitating a good deal of narrative information. This means that not only is the completion of the document a time-consuming task, it is also a qualitatively demanding one. One cannot simply check an appropriate box or mark-sense a cell and move quickly through the process. Each response requires thought and the periodic acquisition of information from agency files. Therefore, the completion of the VIF is a quantitative and qualitative task requiring a good deal of effort on the part of the agency. This problem is compounded by the fact that the release of some of the information may be perceived as a threat to the agency because the data relates to funding, efforts at deinstitutionalization, program accountability, etc., in a documented form. Although the agency may be working hard in all areas, they may perceive themselves as vulnerable to criticism and, therefore, be reluctant to put themselves on record in an evaluative situation. Each of these contingencies, and their combination, may have resulted in the low return rate of VIF's.

Nature of the Clientele

According to the perceptions of the service providers, they had so few HIDD clients that it would not serve a useful purpose for them to complete a VIF. A fact

worth noting is that the perceptions were different in some cases, before the VIF was received by the agency. For example, one agency stated in a correspondence dated 10/12/78 that they served 5 HIDD persons, and had a contract with another agency to serve 31 additional clients, some of whom had hearing impairments. In addition, this agency served "about 60 DVR clients with varying disabilities." The VIF was mailed from the MDP on 10/13/78, and we received a response on 12/11/78 indicating that "currently we have only *one* HIDD client here." Additionally, the letter stated that the hearing impaired clientele "usually . . . have mental health problems rather than developmental disabilities." This statement is in direct conflict with information supplied to us on the original information survey which stated that the agency served persons with hearing impairments, epilepsy, and mental retardation. The area reserved for "other" disabilities (i.e., mental health problems) was left blank.

This situation was by no means unique to this single organization. In fact, other agencies about which there is published information regarding their HIDD population (See Stewart, 1978, *Directory of Resources*) claimed not to serve this group and, therefore, "had no need" for the "Analysis of Services." The question which needs an answer at this point is, "Are the clients really there?" The answer seems to be affirmative according to the published information. Perhaps, the reason for the misrepresentation of the clientele is, in fact, a misperception developed upon a re-examination of the population in view of the information requested on the VIF. Or, the issue might be that, "We have *so few* HIDD clients, it would not be worth our filling out the questionnaire." In either case, the agency's perceptions of the population may have precluded the completion of the VIF and entry into the analysis system.

Administrative Structure

Many agencies maintain an operational format which does not include internal evaluation. A schema of this sort is characterized by the words, "It's not my job!" Many of the agencies that indicated initial interest in the "Analysis of Services" found that they did not have a staff member who had the time and the expertise to complete the VIF. Several organizations attempted to assign different sections to different people, but this affected the consistency of the results unless specific constraints were established in advance. Thus, agencies found that they simply did not have a person to complete the documentation, and the task remained undone.

DISCUSSION

From the preceding information, one might conclude the "Analysis of Services" system was a total failure. This is not true insofar as those agencies completing the VIF were concerned. The following letter confirms this statement.

Mr. Joe Perine
Model Demonstration Program
The Rehabilitation Center
College of Education
The University of Arizona
Tucson, Arizona

Dear Joe:

On behalf of our entire Rehabilitation Services for Multiply Handicapped Hearing Impaired Individuals Project team, I wish to thank you for the analysis you did of our services to hearing impaired developmentally disabled persons. We are, indeed, pleased with your findings. Although it has not been possible to discuss these results at length with the assistant director of our agency, I intend to do so very soon and I am sure we will attempt to follow through on some of your recommendations as soon as feasible. We really do thank you for your kind words. Our Project participants have worked hard in order to achieve success. We are extremely proud of each of them!

It was good having the opportunity to meet you during your recent visit to the Twin Cities. The workshop was positive and we appreciated your contribution.

Next time you come to Minneapolis or St. Paul, please schedule sufficient time to take a tour of our facilities. You would be most welcome any time.

Sincerely,

Barbara Lee, Coordinator
Rehabilitation Services for Multiply Handicapped
Hearing Impaired Individuals

BL:dg

150

It appears that for those organizations that were not threatened by the nature of the system, that had a clear perception of their clientele, and that had an individual who could devote the necessary time and effort, the "Analysis of Services" supplied a valuable assessment of their program and an adjunct to other evaluations.

The MDP experience in analyzing services for HIDD persons was a positive one in that it resulted in the creation of a model for this purpose. A related, unexpected finding was that few schools and agencies were willing to take the time required to analyze their programs. However, this finding appears to underscore the fact that services to HIDD persons are *not* a high priority among schools and agencies across the nation.

The MDP staff is convinced that the HIDD population is much like the deaf-blind population prior to enaction of its special legislation in that (a) existing legislation is not strong enough to *mandate* appropriate programs for them. There are too many loopholes that permit schools and agencies to put off or otherwise overlook HIDD persons, and (b) the needs of severely handicapped HIDD persons require *expensive* services that few schools and agencies can afford without sacrificing other program components.

A final, all-pervading problem that perpetuates the fact of inadequate services for HIDD persons is the lack of personnel training programs in this area. Schools and agencies have a pronounced tendency to employ personnel who are prepared to serve one primary disability group (e.g., the deaf, the mentally retarded, the blind), and this problem is reinforced by teacher training departments within colleges and universities. Chapter 9 focuses upon this problem.

CHAPTER 9

MODELS FOR GRADUATE EDUCATION IN THE HIDD AREA

In the United States today, the individual states have rather rigorous standards for the preparation and certification of personnel who serve the handicapped. This is as it should be since handicapped children have specific problems and needs that require special assistance. However, too often these state standards apply only in specific categories of disability such as the deaf, the blind, the mentally retarded, and certain others. Increasingly, standards are being encouraged, and in some cases implemented via certification, in the preparation of personnel to serve the multiply handicapped. However, these latter attempts are minimal and inadequate since the "multiply handicapped" category is far too all-encompassing for truly meaningful outcomes. For example, the deaf-blind and the blind-mentally retarded are groups that are "multiply handicapped" yet have vastly different needs. A teacher preparing to teach the blind/cerebral palsied individual would have few qualifications to teach the deaf/mentally retarded since the learning needs are quite different in each case and the required teaching skills are not identical.

The Model Demonstration Program attempted to encourage the development of special degree training in the area of serving HIDD persons, but met with only marginal success. Success was achieved in having several graduate students do their internship with the project, and one course on the HIDD population was offered for one semester through the College of Education at the University of Arizona. The course outline and two sample lecture outlines are included in the Appendix.

A major stumbling block to development of teacher training programs in the HIDD area is the lack of certification requirements. State agencies and national groups such as the Council on Education of Deaf (C.E.D.) and the Commission on Accreditation of Rehabilitation Facilities (C.A.R.F.), as well as the American Association of Mental Deficiency (A.A.M.D.) lack specific certification standards for HIDD workers. Without such standards, teacher and counselor preparation programs refuse to attempt to define required knowledges and skills and, as a result, an appropriate degree curriculum cannot be described and implemented.

To be sure, defining the skills and knowledges required for serving a heterogeneous group such as HIDD persons is by no means an uncomplicated task. Yet, these children and adults *do* exist. The invocation of the "Ostrich Syndrome" by certifying bodies and teacher training centers, among others, does not change this need. However, the Ostrich Syndrome was in evidence wherever the MDP turned! Replies received from teacher training and other professional degree

programs boiled down to "Our present degree programs are adequate to meet HIDD needs" or "There are no certification standards for serving HIDD persons, hence we do not know how to develop an appropriate curriculum."

In a partial attempt to respond to this need, the MDP boldly – sans certification standards and sans precedent – developed a statement and proposed curriculum for teachers training at the graduate level to serve HIDD persons. This proposal is presented below for consideration by teacher training programs having a pioneering spirit.

TEACHER PREPARATION TO SERVE THE HIDD

by

Vicki Palm

According to the *1976 American Annals of the Deaf* "Directory of Services," there were then 71 institutions that offered teacher training in deaf education in the U.S. Thirty-eight programs were offered at the undergraduate level and 59 at the graduate level. There were also degrees offered in mental retardation at numerous universities across the country at both the undergraduate and the graduate levels. Teacher training programs in the area of multiple handicaps were, however, much harder to find. In 1976 only four states had programs for teacher training in the area of the deaf-blind. Such training was offered by 5 institutions. One program was available at the undergraduate level and 5 at the graduate level. In light of the fact that deaf-blindness had long been recognized as an unique handicapping condition and that, at a national level, deaf-blind regional programs had already been established to help coordinate services and provide money to programs for these individuals, the lack of teacher training programs in that area was appalling. The hearing impaired developmentally disabled had yet to be recognized as distinct group that needed very specialized services that are uniquely different from those historically offered to either the deaf or the developmentally disabled. It was, therefore, not surprising that teacher training in this area was also sadly lacking.

The state of the art in teacher training in the area of hearing impairment in combination with one or more of the developmental disabilities is currently at a very minimal, if not non-existent, level. Most of the children being served through the educational system are being taught by teachers with degrees in *either* deaf education or mental retardation. Very much harder to find are teachers with undergraduate degrees in mental retardation and masters degrees in deaf education, or visa versa. Because there are few teacher training programs currently available that focus, even globally, on this dual disability group, however, there are few teachers educationally qualified to teach this group. The vast majority of "experts" in this field today have educational certificates in one area (i.e.,deaf education) and a vast amount of experience with this multiply disabled group, but not a degree from a university qualifying them to teach this group.

Why is there a need for such specialized teacher training?

The education of hearing impaired developmentally disabled children is uniquely different from either the education of hearing impaired children or education of developmentally disabled children. When occurring in combination, these disabilities require specially trained teachers who can provide adequate and appropriate programming for both of these disabilities. This highly specialized training should provide the professional with a background in audiology, aural rehabilitation and language and communication development as well as course work in the areas of EMR, TMR serverly and profoundly handicapped; physical, visual, and learning disabilities; and behavior management techniques.

Graduate work in the area of either deaf education or mental retardation rarely provides the professional with this wide variety of needed expertise to deal with the student who has multiple disabilities.

Too often the teacher with an educational background in mental retardation has little or no facility in manual communication. Training is also lacking in the areas of the implications of a hearing loss; developing speech skills in the hearing impaired; the need for, and techniques in, auditory training; appropriate language development techniques for the hearing impaired; as well as less complex issues, such as the care and maintenance of the hearing aid.

On the other hand, those teachers with an educational background in deafness who begin to teach HIDD students are generally lacking in skill in the areas of appropriate behavior management techniques; pre-academic and vocational skills; how to deal with the severely and profoundly retarded; as well as knowledge in other disability areas, such as the visually handicapped, the physically disabled, and the learning disabled.

It is, therefore, necessary for any teacher training curriculum to provide the *trainee* with background and experience in all these necessary areas. The following three sample curriculums are proposed:

1. *Undergraduate Teacher Preparation.* Students preparing at this level to teach HIDD students should take the regular course work for a degree in special education, either MR or deaf education. Electives should be courses in the following areas:

a. *Mental Retardation Major:* Language and speech development for the hearing impaired, audiology, aural rehabilitation, and manual communication.

b. *Deaf Education Major:* Behavior principles, mental retardation, visually handicapped, physically handicapped, behavior disorders.

Practicum experiences should vary widely and include experience with *all* levels of retardation in combination with *all* levels of hearing impairment.

Providing someone with the wide array of courses necessary at the graduate level is a difficult, if not impossible, task without necessitating a two year masters

program. For that reason, the following masters level programs require the student to enter with a bachelor's degree in either mental retardation or deaf education. Class titles and contents are based on courses currently offered at the University of Arizona (1979).

c. *Program of study for those with a deaf education background (B.S.) to a Master's degree:*

Summer I			*Units*
Sp. Ed.	470	Mental retardation	(3)
Sp. Ed.	572a	Physically Handicapped Child	(3)
Summer II			
Sp. Ed.	413	Education of the Visually Handicapped	(3)
Sp. Ed.	573a	Education of Children with behavioral disorders	(3)
Semester I			
Sp. Ed.	419	Behavior principles for the Handicapped Child	(3)
Sp. Ed.	474	Curriculum adaptations for Exceptional Children	(3)
Sp. Ed.	475	Observation and participation in special education programs	(3)
Sp. Ed.	**	Assessment of severely/multiply handicapped students	(3)
Sp. Ed.	4046	Teaching severely/multiply handicapped students	(3)

** A course number has not yet been assigned.

Semester II			
Sp. Ed.	594	Field practice in teaching exceptional children	(6)
or			
Sp. Ed.	593	Internship	(6)
		Elective	(3)
			(36)

d. *Program of study for those with a developmental disabilities background (B.S.) leading to a Master's degree:*

Summer I			*Units*
Sp. H.	589	Principles of audiology	(3)
Sp. Ed.	405	Education of the deaf	(3)
Summer II			
Sp. H.	484	Aural rehabilitation	(3)
Sp. Ed.	581	Language development for the exceptional child	(3)
Semester I			
Sp. Ed.	585	Communication development for handicapped children	(3)
Sp. Ed.	582	Teaching language to handicapped children	(3)
Sp. Ed.	474	Curriculum adaptations for exceptional children	(3)
Sp. Ed.	475	Observation and particiation in special education programs electives (Manual Communication I)	(3)
Semester II			
Sp. Ed.	594	Field practice in teaching exceptional children	(6)
or			
Sp. Ed.	593	Internship	(6)
		Elective (Manual Communication II)	(3)
			(36)

The intent of these proposed curricula is to make it easy for all colleges or universities to adapt their current programs of study to accommodate teacher training in the area of the HIDD. Because of the low priority which is unfortunately given to the HIDD at this time, and the accompanying unfortunate economic position of the trainee who graduates with such a highly specialized degree, it is felt that this is currently the optimum approach to training teachers to successfully serve the HIDD.

The *principles* of these curricula can be utilized by programs preparing counselors, social workers, and others from various disciplines to work with HIDD persons. The goal of such preparation is to combine the critical training of the discipline (e.g., education, psychology, etc.) with the preparation necessary to serve HIDD persons.

SUMMARY

This chapter has attempted to describe the current problems in the area of personnel preparation at the degree level in the area of serving HIDD persons, and to propose means for resolving these problems. Specialized preparation programs are urgently needed and should be vigorously pursued by qualified colleges and universities. Models have been presented as a starting point.

The next chapter discusses short term training needs, accomplishments of the project, and models for future training.

CHAPTER 10

SHORT TERM TRAINING IN THE HIDD AREA: NEEDS, ACCOMPLISHMENT, MODELS

As indicated in Chapter 9, degree level preparation in serving HIDD persons is needed, possible, and feasible, without undue complexities. However, there is also a need for short-term training for personnel who are currently employed in serving HIDD children and adults or who are in a position to advocate for better services and programs for them. This chapter describes the need for this training, what the MDP has accomplished in the area, and the models for short term training the project has developed.

The Need for Short Term Training

Previous chapters have explained that HIDD children and adults are being served by a variety of schools and agencies throughout the country, and that front line service workers are experiencing undue frustrations in their work because they feel unprepared to deal with the special problems of HIDD persons. Moreover, within each state very few agency and school administrators or agency planners appear to possess a sound understanding of the size, problems, and needs of the HIDD population. As a result, far too many HIDD children are not being served at all; those who are being served are too often misdiagnosed and/or underserved; and, little attention is being given to the HIDD population by State Developmental Disabilities Planning Councils, legislated D.D. Protection and Advocacy groups, and programs for the education of the deaf. The contention that the nation lacks sufficient information on the HIDD population, as proposed by Healey (1975), was all too clearly validated by the experiences and formal studies conducted by the MDP.

This lack of information problem was perceived by the MDP as a mandate to produce informational publications and to conduct short term workshops for members of State D.D. Councils, program administrators, frontline service workers, and advocacy groups. Through this training, the findings of the MDP could be widely disseminated and, hopefully, lead to increasing advocacy and improved services for HIDD persons.

Project Training Activities

The MDP training activities were concentrated in five areas: consultation/training sessions with small groups of professionals on-site at schools and agencies that requested assistance; displays of HIDD publications at local, state,

158

regional, and national conferences; presentation of lectures at selected conferences; sponsored orientation sessions for state D.D. Councils; and, sponsored training workshops in selected states.

The first nine months of the project (10/76 – 6/77) was a building period for MDP staff; yet 534 professionals benefited from the training activities of the MDP. See Table 1 for a summary of Year I training activities.

This training set the stage for the project's services component, and clearly resulted in increased activities in the HIDD area in Arizona.

During the second project year reporting period (7/77 – 6/78), the project served more than 800 persons in its training activities. There were several major conferences, including the following:

4/78 Serving Severely Handicapped Deaf Persons in Arizona – A Workshop Co-Sponsored by the Arizona Chapter of the American Deafness and Rehabilitation Association (75 participants)

4/78 Texas HIDD Workshop, Lubbock (60 participants)

4/78 Orientation to the Service Needs of HIDD Persons for the Sonoma (CA) State Hospital (130 Service Workers)

The third and final project reporting period (07/78 – 07/79) was a time of extensive training activities for the MDP. During this period of time, a total of 794 school and agency workers as well as advocacy group representatives were provided with training totaling 241 hours or 11,970 man/hours. Tables 2 and 3 summarize these training activities. Chart 1 shows major training locations. Consultation, special training, and exhibits reached 1,103 additional persons. (Table 3)

Finally, in July 1979, the project held additional workshops in the states of Maryland and North Carolina, attended by 150 participants.

Thus, over the 36 months of the Model Demonstration Program a total of more than 3,000 administrators, service workers, teachers, and advocates received training in the HIDD area from project staff. This number excludes some workers who either visited MDP displays during national conferences and received MDP published informational materials.

A highlight of MDP information dissemination activities was the invited appearance of the project director before the subcommittee on the Handicapped of the Committee on Human Resources, United States Senate, on March 10, 1978. These Subcommittee hearings on the Rehabilitation Amendments of 1978, permitted the project to present testimony concerning the HIDD population (see *Rehabilitation Amendments of 1978: Hearing Before the Subcommittee on the*

TABLE 1

MDP YEAR I (10/76 - 06/77)*
TRAINING ORIENTATION ACTIVITIES

DATE	ACTIVITY	PARTICIPANTS
12/05/76	Introduction to the MDP	45 agency supervisors
12/08/76	Overview of the MDP	30 ADDPAC members
01/27/77	State Needs Assessment Workshop	98 School/agency reps.
02 & 03/77	Sign Language class	12 staff from Beacon Foundation
02/77	Orientation to MDP	4 members, ASDB Board
03/08/77	Orientation to MDP	15 members, Advisory Committee on Communication Disorders, DES
04/21/77	Orientation to curriculum goals of MDP and organization of statewide Curriculum Council	10 supervisors
06/10/77	Two-day Workshop "Gestural and Creative Sign Language"	10 HIDD teachers, speech pathologists
06/15/77	One-day Symposium on Education of HIDD Persons	60 members from DD programs in California
06/22/77	Orientation to the MDP and Curriculum Development for HIDD Persons	40 participants
06/28/77	Orientation to the MDP	25 supervisors
06/30/77	Presentation on the MDP	15 teachers
	TOTAL	534

*Reporting year ended 6/30/77

Handicapped. Washington, D.C.: U.S. Government Printing Office, March 10, 14, 1978, P. 205-234).

Models of Training

The nature of the training activities cited in the foregoing pages in this chapter represents the type of focus that regional training and technical assistance centers for the HIDD population could be expected to maintain. The target audiences represented important and influential groups from a services and advocacy standpoint, and consequently similar groups should be targeted for future training activities. In this sense, the methodology followed by the MDP represents a viable model.

The actual curriculum used in training advocates and workers is crucial. Too often, a general, overly global curriculum is used to reach many different groups.

The MDP, recognizing the potential hazards of a diffused training program, developed a training curriculum specifically for members of state developmental disabilities councils. This curriculum offers a six-hour concentrated training module consisting of lectures, recorded materials, video-taped materials, overhead transparencies, and a publication (Stewart, L. *Hearing Impaired and Developmentally Disabled Persons: An Orientation and Resources Guide for State Developmental Disabilities Councils.* Tucson: The Rehabilitation Center, The University of Arizona, 1978).

This curriculum, offered in a one-day, six-hour "package," consisted of the following:

- The HIDD Population (Lecture) Definitions, Characteristics, Numbers
- Recording ("How They Hear")
- Problems and Needs of the Population (Lecture)
- Service Models (Lecture)
- Coordination Issues (Lecture)
- The State D.D.Council: Hope for the Future (Lecture)
- Videotape "Total Commuication for HIDD Persons"
- Conducting a Needs Assessment (Lecture)
- Human and Technical Resources (Lecture)
- The Future ("How the D.D. Council Can Help") (Lecture)

TABLE 2

MODEL DEMONSTRATION PROGRAM:
Major Training/Technical Assistance Activities
October, 1978 - June, 1979

	Training Sites	Date	Co-Sponsors	Length	Purpose	Disciplines Participants	Number of Participants
1.	Salt Lake City, Utah	10/78	Utah D.V.R.	6 Hours	Orientation to HIDD	Voc. Rehab. Counselors	30
2.	Austin, Texas	11/78	Texas D.D. Council	1 Hour	Orientation to HIDD	D.D. Council, Agency Administrators	35
3.	San Juan, Puerto Rico	12/78	Puerto Rico D.D. Council	6 Hours	Orientation to HIDD	D.D. Council Members	25
4.	Phoenix, Az.	12/78	Arizona D.D. Planning and Advocacy Council	1 Hour	Progress Report, needs statement	D.D. Council Members	30
5.	Tucson, Az.	1/79	National Interpreter Training Consortium	80 Hours	Intensive training for interpreters with severely handicapped deaf people	Interpreters for the deaf	50
6.	Raleigh, N.C.	1/79	N.C. State V.R. and D.D. Council	8 Hours	Planning for State HIDD Workshop	Agency Administrators	6
7.	San Antonio, Texas	5/79	Texas Tech University MR R&T Center	20 Hours	Orientation to HIDD	Administrators, teachers, psychologists, rehab. counselors	64
8.	Syracuse, N.Y.	3/79	Onondaga/Madison BOCES Program	8 Hours	Planning for statewide workshop	Administrators, agency planners, teachers, rehab. counselors	12
9.	Concord, N.H.	3/79	N.H. D.D. Council	22 Hours	Orientation to HIDD	Counselors, teachers rehab. workers, administrators	62
10.	Honolulu, HI	4/79	Hawaii D.D. Council, Hawaii School for Deaf	16 Hours	Orientation to HIDD	Teachers, counselors parents, administrators	62
11.	Honolulu, HI	4/79	Hawaii D.D. Council	4 Hours	Orientation to HIDD	D.D. Council, staff	12
12.	Lynchburg, VA	4/79	Lynchburg Training School & Hospital	14 Hours	Orientation to HIDD	Teachers, counselors, administrators, others	50
13.	Minneapolis, MN	5/79	Minn. D.D. Council	16 Hours	Orientation to HIDD	Teachers, counselors, psychologists, parents, administrators	94
14.	Des Moines, IA	5/79	Iowa D.D. Council	3 Hours	Orientation to HIDD	D.D. Council Members	5
15.	Des Moines, IA	5/79	Goodwill Industries of Des Moines	14 Hours	Orientation to HIDD	Teachers, counselors, psychologists, parents, administrators	30
16.	Bloomington, IL	5/79	D.D. Council	3 Hours	Orientation to HIDD	D.D. Council members	10
17.	Chicago, IL	5/79	Ill. D.D. Division	4 Hours	Orientation to HIDD	Teachers, audiologists, speech therapists, others	70
18.	Little Rock, AR	6/79	Arkansas D.D. Division	6 Hours	Orientation to HIDD	D.D. Council members, speech and hearing, teachers, administrators	40
19.	Lansing, MI	6/79	Mich. Division of Mental Health, Exas D.D. Council	6 Hours	Orientation to HIDD	D.D. Council, teachers, speech & hearing, administrators, psychologists	95
20.	Ann Arbor, MI	6/79	University of Michigan (ISMRRD)	3 Hours	Orientation to HIDD materials	Teachers	12
					Total Number of Participants:		794
					Total Number of Training Hours:		341
					Total Manhours in Training*:	11,970	

*Derived by multiplying number of training hours in each training activity by the number of participants in that activity, then adding the "products" for the 21 separate activities.

CHART I

GEOGRAPHICAL DISPLAY OF MAJOR TRAINING ACTIVITY SITES 1978-1979

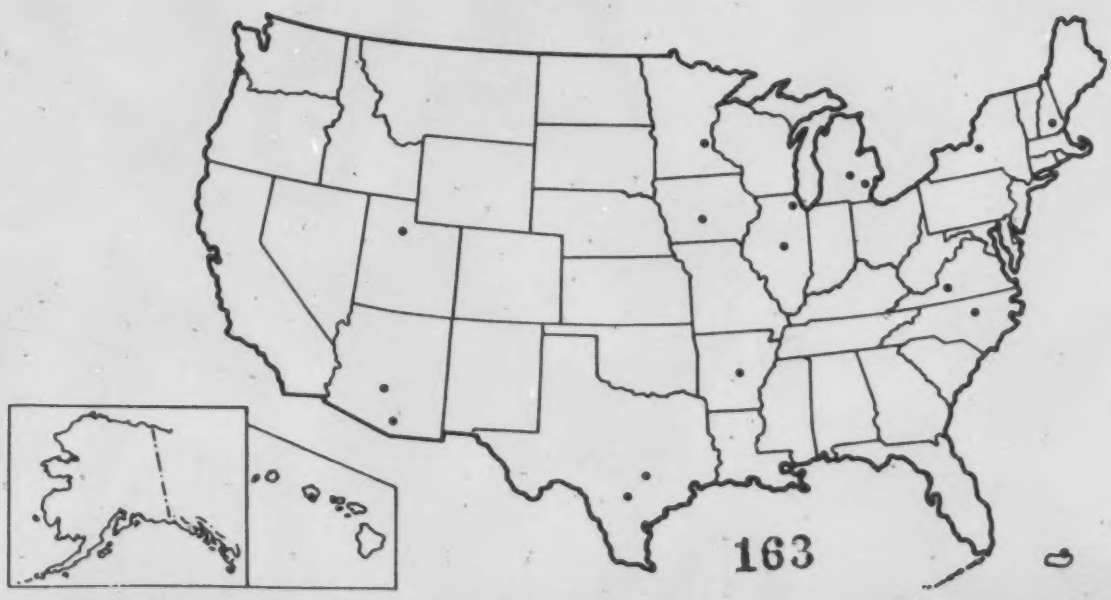


TABLE 3

MODEL DEMONSTRATION PROGRAM:
Supplemental Training/Technical Assistance Activities
October, 1978 - June, 1979

Training Site	Date	Co-Sponsors	Length	Purpose	Disciplines Participants	Number of Participants
1. San Diego, CA	10/78	National Sign Language Symposium	28 Hours	Display of MDP Products	Interdisciplinary conference	200+
2. Picacho, AZ	11/78	Picacho School District	4 Hours	Inservice Training (HIDD)	Teachers	6
3. Tucson, AZ	11/78-1/79	Tucson School District	20 Hours	Consultation on HIDD Programs	Teachers	5
4. Phoenix, AZ	11/78	State Dept. of Education	12 Hours	Display of MDP Products	Educators	200+
5. Tucson, AZ	12/78	U.A. Special Education Department	1 Hour	Orientation to HIDD	Teachers in Training	16
6. Phoenix, AZ	2/79 3/79	Maricopa Co. Assn. of Retarded Citizens Center	12 Hours	Inservice Training (HIDD)	Teachers, Technicians	20
7. Kingman, AZ	2/79	Kingman Public Schools	10 Hours	Sign Language w/HIDD	Teachers, Parents	20
8. Tucson, AZ	2/79	Tucson School District	2 Hours	Inservice Training (HIDD)	Teachers	20
9. Washington, D.C.	1/79	Gallaudet College	1 Hour	Lecture on Severely Handicapped	Faculty, staff	200+
10. Tucson, AZ	5/79	U of A Rehab. Center	48 Hours	Academic class on serving HIDD Persons	Counselors, Psychologists	6
11. Tucson, AZ	4/78	Psi Chi Honor Society, Psych. Dept. of U.A.	1 Hour	Lecture on Deafness	Undergraduate, graduate students in psychology	50
12. Ontario, CA	4/79	UCLA/NPI	10 Hours	Consultation on HIDD Research	Administrators, Psychologists	5
13. Grand Junction, CO	5/79	State Home & School	14 Hours	Inservice Training	Teachers, Speech & Hearing, OT, PT	30
14. Tucson, AZ	5/79	Rehab. Center, U of A	3 Hours	Lecture on Counseling the Deaf	Graduate students	25
15. St. Paul, MN	5/79	St. Paul-Ramsey Hospital	6 Hours	Inservice Training on HIDD	Physicians, nurses, psychologists, social workers, interpreters	10
16. San Jose, CA	6/79	Agnew State Hospital	10 Hours	Inservice Training	Teachers, OT, PT, Speech & Hearing	30
17. Miami Beach, FL	5/79	A.A.M.D.	32 Hours	Display of MDP Products	Interdisciplinary groups, parents, advocates	200
18. Miami Beach, FL	5/79	AAMD	2 Hours	Lectures to Special interest groups	Speech & Hearing, teachers	30
19. Tucson, AZ	6/79	National Interpreter Training Consortium	3 Hours	Lectures on HIDD	Interpreters	40
					Total Participants	1,103

Total Parts:

Total Participants

This curriculum can be shortened by condensing some topics, and also by giving a one-hour overview and then assigning the previously cited guide as an "outside reading."

The state workshop model was similar to the State D.D. Council training module except the schedule was designated to cover two days and (a) the Council focus was eliminated, (b) the guide book was not used, (c) other published materials of a service nature were used, (d) provisions were made for local programs to describe their services for HIDD persons, and (e) the participants met in special interest groups (e.g., education, rehabilitation, mental health, adult services, institutions, etc.) to discuss problems, and to identify and list future needs in order of priority.

Each state where a HIDD statewide workshop was held developed its own schedule for its HIDD workshop. However, fairly typical was the following:

Day One

- Introduction to the HIDD Population -- Definitions, Characteristics, Numbers
- Service Needs of HIDD Children, Adults
- Current Problems in Serving HIDD Persons
- Local and State Programs for HIDD Persons
- Funding Resources for HIDD Programs
- The State D.D. Council and Advocacy with HIDD Persons

Day Two

- Legal Foundations of Service for HIDD Persons
- Conducting a Needs Assessment: How to Do It
- Small Group Discussions
- Identifying Needs and establishing their priority.

The publications disseminated during these workshops were designed to complement the above topics.

An effective model of short term training will always call for participation of members of a variety of disciplines as well as professionals from both the area of services for the hearing impaired and the area of services for the developmentally

disabled. Moreover, advocacy groups and consumer groups must be represented among the participants.

University Affiliated Facilities (UAFs) are ideal sponsors of ongoing training workshops in the HIDD area. The Research and Training Centers on Mental Retardation and the R & T Centers on Deafness, under the Rehabilitation Services Administration (HEW), are also prime candidates to carry on this training.

SUMMARY

This chapter has presented the work of the Model Demonstration Program over a three year period in the area of training professionals to serve HIDD persons. Models for such training have been outlined, and future sponsors for such training have been identified. The next chapter lists published products of the Model Demonstration Program which can be used in such training.

CHAPTER 11

PUBLICATIONS AND RELATED DISSEMINATION ACTIVITIES OF THE MODEL DEMONSTRATION PROGRAM

Over the life of the Model Demonstration Program, a variety of publications was produced to assist in training and orientation activities.

These publications are listed below:

Model Demonstration Program HIDD Brochure

Mono. No. 1 HIDD Persons in the U.S. Definitions, Causes, Effects, and Prevalence Estimates

Mono. No. 2 Education Services for HIDD, Review of Programs at State Department of Education Level

Mono. No. 3 Preliminary Survey of Services to HIDD Students in Residential Schools

National Directory of Residence, Education, and Training Facilities Serving HIDD

Arizona's Resources for HIDD Persons

Serving HIDD Persons in Arizona

Severely Handicapped Deaf People: Programs for Administrators and Planners

HIDD Orientation and Resource Guide - State DD Councils

Family Support Programs

Assisting Employers of HIDD Workers

Education Programs for HIDD Persons

Mainstreaming the Hearing Impaired Child

Residential Facility Programs for HIDD

Normal Auditory Development

Audiological Testing and Terminology

Care and Maintenance of the Hearing Aid

How to Help a HIDD Person Benefit from a Hearing Aid

Audiology with HIDD Persons

Fact Sheet: *Counselors in Training*

Counseling Families of HIDD Persons

Counseling Services for the HIDD

Resource Materials for Teaching HIDD Persons

Vocational Programming with HIDD Persons

A Guide to the Legal Rights of HIDD Persons for Educators, Habilitation Specialists, Employers

A Parent's Guide to Legal Rights of HIDD Persons

Consumer's Guide to Public Law 94-142

Hearing Impaired Developmentally Disabled Children and Adults: How We Can Help

An Introduction to Hearing Impairment for Workers with the Developmentally Disabled

The Individualized Learning Systems (in preparation, August 1979)

The Teacher Aide with HIDD Children (in press, August 1979)

These publications were mailed to the professional groups, individuals, schools, and agencies thought by MDP staff to be in need of the information. They were also used, selectively, at various training workshops.

Cumulatively, more than 50,000 copies of these various publications were distributed across the nation.

A periodical newsletter (The HIDD Advocate) was also published and disseminated to selected audiences.

In early 1979, a "feedback evaluation sheet" was inserted with all publications in an effort to obtain reader critical evaluations of MDP products. The great majority (total: 103) of the evaluation sheets returned were positive; the negative evaluations received (total: 12) were primarily because the material was known to the reader. Interestingly, administrators returned the evaluation sheets at a much higher rate than did direct service providers (frontline workers).

Other products of the project were:

- A videotape on sign language
- A slide/tape production on HIDD children
- Videotape on teaching HIDD persons

These were used on a limited scale for project training purposes, but some were purchased at cost by selected professionals.

The production of published materials by project staff proved to be a fundamental, indispensable aspect of informational and training efforts. Up to the time of the project, the literature on the HIDD population was meager and hard to find. Thus, the project produced its own materials and helped to fill an important gap in the literature.

CHAPTER 12

ASSESSMENT OF THE MODEL DEMONSTRATION PROGRAM

This chapter presents a global assessment of the Model Demonstration Program. The project was not designed as a rigorous research project, hence no plans were made to conduct "before and after" studies or to collect a large body of statistical data for comparative purposes. Rather, the assessment of the project was to be done in such a manner that the question, "Did the Model Demonstration Program for Hearing Impaired Developmentally Disabled Persons do what it said it would do in its proposal?" could be answered in a practical, meaningful way.

Chapter 1 presented the background to the project; Chapter 2 described the proposed M.D.P. and what it hoped to accomplish. Chapters 3-11 have described project activities and some of the outcomes of these activities.

The following summary is offered as a means of assessing the project:

The MDP was to advance the state of the art in serving HIDD persons nationally.

> We of the MDP believe we have accomplished this goal in substantial areas, as evidenced by service, published products, and training activities.

The MDP was to produce models of services for HIDD persons.

> We believe we have succeeded with this goal in several important areas, but we feel that only a beginning was made. Much more is needed that will take years to accomplish and the collaborative efforts of service providers, researchers, and the public.

The MDP was to serve 160 HIDD children and adults over a three year period.

> We served more than 400 HIDD persons during the first 18 months of the project, and completed our activities with services to more than 1,000 HIDD individuals.

The MDP was to provide short-term training to 675 workers in the HI and D.D. areas.

We provided training to more than 3,000 workers, administrators and advocates during the life of the project.

The MDP was to provide training to 28 graduate students preparing to work with HIDD persons.

We provided indepth training to approximately 10 graduate students and orientation lectures covering from one to five hours to more than 50 graduate students. However, we were not successful in seeing the establishment of a degree program in the area of serving HIDD persons.

The MDP was to prepare informational materials on HIDD persons.

We published more than 30 separate publications dealing with the HIDD population.

The MDP was to establish and operate a model demonstration center for HIDD persons.

Due to local problems and limitations, our success in this area was limited. We were not able to obtain the facilities we needed. However, by utilizing the "cooperative" concept, we were able to conduct the basic demonstration activities that were essential and, through use of borrowed space and a mobile unit, develop innovative services.

The MDP was to conduct HIDD population studies.

We were able to obtain extensive, detailed information on the HIDD population and the current status of service efforts on its behalf.

The MDP was to work with the UAF System and encourage members to conduct research and training activities with the HIDD population.

All MDP publications were sent to all UAF centers. A letter was sent to all UAF centers encouraging them to work with HIDD persons and offering the resources of the MDP as appropriate. Several UAFs cooperated with the project in conducting research and training activities.

The MDP was to demonstrate a model for coordinating statewide services for HIDD persons.

We developed several models, but had limited success in their implementation within Arizona due to the low priority given to services for HIDD persons.

The MDP was to demonstrate the establishment of a registry of HIDD children.

UTAH STATE BOARD OF EDUCATION
UTAH STATE BOARD FOR VOCATIONAL EDUCATION
250 East Fifth South Street, Salt Lake City, Utah 84111
WALTER D. TALBOT, STATE SUPERINTENDENT OF PUBLIC INSTRUCTION

July 12, 1979

Dr. Larry Stewart
Project Director
Model Demonstration Program
The Rehabilitation Center
College of Education
University of Arizona
Tucson, Arizona 85721

Dear Larry:

Your visit here in October and November of 1978, during which you delineated the HIDD program to our Rehabilitation Counselors, has had a continuing impact--not so much in terms of change of program or anything so drastic, but rather in the nature of change of attitude of these counselors toward deafness and those who have additional disabilities. It's my personal feeling that a change of attitude usually must precede program change.

At any rate, the general counselors whom I have known for a long time have gradually demonstrated interest and have actually asked for information on learning signs; have become more friendly towards me; and now call more frequently seeking information and advice on how to handle some deaf problems they meet.

I received excellent feedback after your presentation. So, all in all, I must extend my thanks to you, again, for the considerable help.

Sincerely,

ROBERT G. SANDERSON, Coordinator
Services to the Deaf
Division of Rehabilitation Services

/mc

VAUGHN L. HALL, Associate Superintendent
Office of Adult, Vocational, and Rehabilitation Services

HARVEY C. HIRSCHI, Administrator
Division of Rehabilitation Services
Telephone (801) 533-5991

Bruce Babbitt
GOVERNOR

ARIZONA DEPARTMENT OF ECONOMIC SECURITY
VOCATIONAL REHABILITATION
100 East Alameda, Suite 411
Tucson, Arizona 85701
882-5035

Bill Jamieson, Jr.
DIRECTOR

11 July 1979

Larry G. Stewart, Ed.D.
Project Director
Model Demonstration Program
The Rehabilitation Center
College of Education
University of Arizona
Tucson, Arizona 85721

Dear Larry:

It is my opinion that the Model Demonstration Program for Hearing Impaired Developmentally Disabled people in Arizona has been very successful.

The program has been a great help in determining the vocational potential of many of our most severely disabled deaf clients. The evaluation recommendations have assisted our counselors in formulating realistic rehabilitation plans which are extremely valuable time-wise as well as monetarily.

It is our hope that similar services for the hearing impaired, developmentally disabled will be available after September 30.

Sincerely yours,

Andres G. Renteria
Program Manager

AGR:bc

173

WILLIAM G. MILLIKEN, Governor

V. A. STEHMAN, M.D.
Acting Director

STATE OF MICHIGAN
DEPARTMENT OF MENTAL HEALTH
LEWIS CASS BUILDING, LANSING, MICHIGAN 48913

July 11, 1979

Larry G. Stewart, Ed.D.
Project Director
Model Demonstration Program
The Rehabilitation Center
College of Education
The University of Arizona
Tucson, Arizona 85721

Dear Dr. Stewart:

I am writing in response to your letter of July 2, 1979, in which you requested a statement from the Department of Mental Health regarding the impact of the Model Demonstration Program on the hearing impaired/developmentally disabled population in our state.

In my opinion, the Model Demonstration Program presented by you and your staff was well received by the 104 participants of the workshop. It is too early to ascertain whether there will be an impact on the HI/DD population. However, I am informed that the interest created by the information imparted has generated considerable enthusiasm in developing cooperation among the various agencies represented, and the role of advocacy will ultimately bring increased services and programs for the HI/DD citizens.

May I take this opportunity to thank you and your staff members for an outstanding workshop.

Sincerely,

V.A. Stehman, M.D.

VAS/LJW/jg

MICHIGAN
THE GREAT LAKE STATE

174

Texas Tech University
BOX 4610 / LUBBOCK, TEXAS 79409
RESEARCH AND TRAINING CENTER IN MENTAL RETARDATION / (806) 742-3131
Training Division / (806) 742-3970

July 25, 1979

Dr. Larry G. Stewart
Model Demonstration Program
The Rehabilitation Center
College of Education
The University of Arizona
Tucson, AZ 85721

Dear Dr. Stewart:

I would like to take this opportunity to give you our perceptions concerning the impact of the Model Demonstration Program on the State of Texas.

The workshop held in San Antonio, Texas, March 20-22, 1979, concerning the HIDD population had an exceptionally positive response from some 75-80 participants. (On a rating scale from 1 to 10 the mean score for the overall conference, which included speakers from across the nation as well as your own staff, was 7.65 and the mode was 9.65.) Many favorable remarks by the participants during and after the conference confirmed these statistics. The wealth of materials provided by you and your staff have helped provide a sense of continuity to even the more creditable programs.

The presentations by Joe Perine and you were well organized, highly informative, and motivational. We appreciate your professional attitudes and hard work. I understand your grant is winding down in its third year. If your other workshops, inservice meetings, and conferences have been as well organized and informative as this one, it will be unfortunate to see it come to an end.

It was a pleasure working with you in this endeavor. If we can be of any assistance for the future, please do not hesitate to contact us.

Sincerely,

R.A. Wade
Project Training Officer

RAW/rjt
cc: Jerry D. Parham

GEORGE R. ARIYOSHI
GOVERNOR OF HAWAII

STATE OF HAWAII
STATE PLANNING AND ADVISORY COUNCIL
ON DEVELOPMENTAL DISABILITIES
P. O. BOX 3378
HONOLULU, HAWAII 96801
TELEPHONE: 548-5994; 521-6666

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EXECUTIVE SECRETARY

July 26, 1979

Larry G. Stewart, Ed. D, Project Director
Model Demonstration Program
The Rehabilitation Center
College of Education
The University of Arizona
Tucson, Arizona 85721

Dear Dr. Stewart:

Thank you for your assistance regarding Hearing Impaired Developmentally Disabled persons in Hawaii. We appreciated the opportunity to meet with you to share ideas and information.

Briefly, we believe that the Model Demonstration Program's contact in Hawaii has had a positive impact on Hawaii. The seminar and the two-day workshop were highly structured, well-organized, and presented professionally. The materials and information shared by the Program staff will be an additional base of knowledge, which can now be pulled upon at any time here in Hawaii.

We believe that the interchange between the Arizona Program's staff and the Hawaii participants was a growth producing process that will be of benefit to all, for some time to come.

Thank you again for your time and efforts on behalf of Hearing Impaired Developmentally Disabled people in Hawaii.

Sincerely,

Lily I. Wang
Executive Secretary

LIW:bjv

176

THE UNIVERSITY OF ARIZONA
HEALTH SCIENCES CENTER
TUCSON, ARIZONA 85724

COLLEGE OF MEDICINE
OFFICE OF THE DEAN
[redacted]

February 13, 1979

MEMORANDUM

TO: Larry G. Stewart Ed.D.
c/o Rehabilitation Center
College of Education

RE: HIDO

Larry, I have just reviewed the Orientation and Resources Guide that you have prepared. It is a model document. Congratulations. I am pleased to have been a part of the early discussions on "hatching" this instrument and the demonstration program.

Best wishes.

Louis J. Kettel, M.D.

LJK/lmb

177

STATE OF ARKANSAS
Bill Clinton, Governor

DEPARTMENT OF HUMAN SERVICES
Gail S. Huecker, Director

DIVISION OF MENTAL RETARDATION-
DEVELOPMENTAL DISABILITIES SERVICES
Dr. Joseph P. Cozzolino, Commissioner

Suite 400, Waldon Building 7th & Main Streets Little Rock, Arkansas 501/371-1377

July 10, 1979

Mr. Larry G. Stewart, Ed.D.
Project Director, Model Demonstration Program
The Rehab. Center, College of Education
The University of Arizona
Tucson, Arizona 85721

Dear Mr. Stewart:

I would like to respond to your request concerning comments on the assessment of the M.D.P. I am the administrator of our central office staff development section. We recently coordinated a training session with the Model Demonstration Program. The participants were very enthusiastic about the program. Representatives of community programs (Day Service Centers) residential facilities, and Client Placement and Referral Services attended.

Staff Development has just completed a state-wide needs assessment. Many teachers indicated a continuing need for more information in the area of the hearing impaired-developmentally disabled. The information received from the M.D.P. served to enlighten many, in the areas of research and new programs being developed for the HIDD.

The brochures and resource materials were made available to others who could not attend. Many have commented that these were excellent resources. They have asked for more, including copies of the video tapes (which I hope we will be able to purchase this year) and for additional information on how to council with parents. Several also requested information on working with both the hearing and visually impaired.

Again, I think Carol and Vicki did an excellent job of informing the group on information pertinent to the HIDD population.

I hope the program will be continued and that we will be able to participate in a similar, or advanced, training session this fall or next spring.

Sincerely,

Ann Johnson

cc: Mary Eddy Thomas

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Arkansas HB DDS is in compliance with Titles VI & VII of the Civil Rights Act and is operated, managed and delivers its services without regard to sex, race, color or National Origin

178

DEPARTMENT OF INSTITUTIONS
RAYMOND LEIDIG, M.D. Executive Director

DIVISION OF DEVELOPMENTAL DISABILITIES
SHARON O'HARA, Director

STATE HOME AND TRAINING SCHOOL
WILLIAM H. JACKSON, Superintendent
P.O. Box 2568, Grand Junction, Colorado 81501
Telephone (303) 245-2100

July 9, 1979

Larry G. Stewart, Ed. D.
Model Demonstration Program
Rehabilitation Center
College of Education
The University of Arizona
Tucson, Arizona 85721

Dear Dr. Stewart:

The State Home and Training School, Grand Junction hosted a workshop presented to our staff and staff from local community programs by representatives of the Hearing Impaired/Developmentally Disabled Model Demonstration Program. All comments and reactions of participants expressed to me were positive.

The HIDD population presents real dilemmas to those who must program for them. There are simply too few trained to work with this specific disability group. The staff we have were and are groping for direction in which to take their program.

Your project was the first and only source of training we could provide at reasonable cost to our staff outside of the regional deaf blind structure. The training was appropriate to our needs and has impacted on our ability to serve a difficult segment of our clientele.

Sincerely,

Jerry Smith
Special Programs Coordinator

JS/hs

ARIZONA DEPARTMENT OF ECONOMIC SECURITY

Bruce Babbitt
GOVERNOR

1717 WEST JEFFERSON • PHOENIX, ARIZONA • P.O. BOX 6123 85005

Bill Jamieson, Jr.
DIRECTOR

Larry G. Stewart, Ed.D., Project Director
Model Demonstration Program
The Rehabilitation Center
College of Education
The University of Arizona
Tucson, Arizona 85721

Dear Larry:

Thank you for your letter and for the opportunity to comment on the impact of the Model Demonstration Program for Hearing Impaired/Developmentally Disabled Persons.

Services to severely disabled people are a prime target of my administration. As a result of your efforts of the past three years, there have been significant advances in awareness to the needs of hearing impaired/developmentally disabled persons. Publications and technical assistance to field offices help our staff identify and address the needs of this population. Your mobile evaluation unit benefits the rural areas of the state where audiometric testing was not previously available.

The main impact is on services for the mentally retarded, while vocational rehabilitation services also benefits from the technical assistance and instruction. Several program changes are being considered in the Arizona Training Program structure as a direct result of your project, and some have already been implemented. Your work in the schools will become evident as these people get older and enter the DES structure.

I am confident we will continue to benefit from your project's work with the school-aged hearing impaired/developmentally disabled population. I look forward to seeing you soon.

Sincerely,

Bill Jamieson, Jr.

BJJ:WRS:LS

ARIZONA DEPARTMENT OF ECONOMIC SECURITY
Rehabilitation Services Administration
1400 West Washington
Phoenix, Arizona 85007

Bruce Babbitt
GOVERNOR

Bill Jamieson, Jr.
DIRECTOR

July 31, 1979

Larry G. Stewart, Ed.D., Project Director
MOdel Demonstration Program
The Rehabilitation Center
College of Education
The University of Arizona
Tucson, Arizona 85721

Dear Larry:

I am pleased to submit this letter as a project evaluation of your impact on vocational rehabilitation services to hearing impaired developmentally disabled people.

It is difficult to identify any single area where services have benefitted, but overall, our staff serving hearing impaired people are more aware of the unique needs of people with additional developmental disabilities. This awareness seems to have made the agency more accessible to hearing impaired developmentally disabled people, as may be indicated in the increased numbers of severely disabled hearing impaired clients served over the past three years. We will, no doubt, see the results of your work in the school systems as these people enter the Vocational Rehabilitation Program.

Workshops have given our staff a broader insight to problems encountered by people with hearing impairment and developmental disabilities. There was attendance at the Minimal Language Competency Workshop, and the Arizona Deafness and Rehabilitation Association Workshop by our staff. Your support of the group home at the Community Outreach Program for the Deaf in Tucson has allowed our staff to broaden the scope of services to HIDD clients. Publications from your project will be a continual resource for our staff in serving this population.

We are proud that Arizona was targeted as the sight for the Model Demonstration Program, and look forward to continuing our capacity to serve hearing impaired developmentally disabled people in the Vocational Rehabilitation Program.

Sincerely,

Thomas G. Tyrrell
Administrator

STATE OF MINNESOTA

STATE PLANNING AGENCY
101 CAPITOL SQUARE BUILDING
550 CEDAR STREET
ST. PAUL, 55101

July 26, 1979

Larry G. Stewart, Ed.D.
Project Director
Model Demonstration Program
The Rehabilitation Center
College of Education
The University of Arizona
Tucson, Arizona 85721

Dear Dr. Stewart:

Marylee Fithian asked me to respond to your letter of July 2, 1979 regarding the MHMI Workshop conducted here in Minnesota. In particular, you wanted to know our opinion as to the impact that the Model Demonstration Program has achieved here in Minnesota.

I consulted with Marylee and with Dr. Steven Chough, as well as with Barbara Lee of the St. Paul Rehabilitation Center Program for the Deaf.

Regarding the immediate impact of the workshop, it appears that there was a definite increase in awareness of the issues/problems of MHMI. Along with this, as the workshop developed, there was an increased identification of special needs of this population of the deaf and hearing impaired who also have other disabilities.

Secondly, in an immediate sense, the audience was considerably impressed with your extensive background and your skillfulness in explaining in human terms the challenges that MHMI people face in life.

Another immediate result, obviously, was that the workshop brought together hearing and nonhearing professionals whom they had not known before at least well enough to conduct fluent communications. For example, I have talked on several occasions recently with Barbara Lee, Dr. Chough, and others on various subjects and I think I can speak on Marylee's behalf that her communications with the deaf community have also increased.

As far as the long-range impact in Minnesota regarding needs of the MHMI population, that is not easy to assess. I have heard that some concerned people in northern Minnesota, Duluth area, who attended the workshop, may be planning to do a local workshop as a follow-up to the May workshop in Minneapolis.

The various recommendations submitted by each small group have been typed and will be submitted for consideration by the Minnesota DD Council.

Perhaps we would be able to give you more information about impact if we could review the participants' evaluation sheets which were submitted to you at the end of the workshop. We would like to see copies of these evaluation sheets if they are available to us.

In summary, the workshop had a clear cut, immediate impact of increasing knowledge and understanding of the meaning of MHMI. It has also had a measurable increase in communication amongst staff persons in Minnesota who work directly with serving the needs of MHMI population.

Sincerely,

Frank Thimmesch

FRANK THIMMESCH, Planner
Developmental Disabilities
Planning Office

FT:j

"AN EQUAL OPPORTUNITY EMPLOYER"

ASSOCIATES IN HUMAN DEVELOPMENT
Rehabilitation and Developmental Psychology
3820 East Bellevue Suite A
Tucson, Arizona 85716
(602) 327 5209

Larry G. Stewart, Ed.D.
Rehabilitation Psychology

Bridget Tetley, M.S., RN
Substance Abuse

Marsha L. Dunn, M.Ed., OTR
Occupational Therapy

Daniel B. Overbeck, Ph.D., FAAMD
Developmental Psychology

Alan J. Tyler, M.S., CRC
Biofeedback Therapy

July 6, 1979

Larry G. Stewart, Ed. D., Director
Model Demonstration Program
The Rehabilitation Center, UArizona
Tucson, Arizona 85721

Dear Larry:

I am very pleased to respond to your request for my perceptions of the impact of the project in Arizona. As I have stated to you (and many others...) before, I feel that the MDP has played a large and vital role in the sensitizing of Arizona's state administration to the needs of the sensory-impaired, developmentally disabled citizen. Gratefully, your vocal, effective advocacy for the hearing impaired person with developmental disabilities has also heightened the state's awareness of the need for services to the visually impaired individual as well.

You, and the staff of your project, have taken an active, highly visible role---bringing the needs of the HIDD person to widespread attention, identifying alternative strategies for addressing those problems and facilitating the motivation of state and private agencies in directing their energies to improve the service delivery to HIDD persons.

The efforts of the MDP to further enhance service delivery to HIDD persons by providing effective training and information has represented a unique strength of the project; not only have you and your staff been able to derive and elaborate effective strategies, but you have expended great energy in teaching others how to employ those strategies so that they need not "re-invent the wheel" in their attempts to improve services to HIDD persons.

I hope that this letter will be of some assistance to demonstrating the uniqueness and desirability of your program.

Regards,

Daniel B. Overbeck, Ph. D., FAAMD
Applied Developmental Psychologist

ASSOCIATES IN HUMAN DEVELOPMENT
Rehabilitation and Developmental Psychology
3020 East Bellevue Suite A
Tucson, Arizona 85716
(602) 327 5209

Larry G. Stewart, Ed.D
Rehabilitation Psychology

Bridget Tetley, M.S., RN
Substance Abuse

Marsha L. Dunn, M.Ed., OTR
Occupational Therapy

Daniel S. Overbeck, Ph.D., FAAMD
Developmental Psychology

Alan J. Tyler, M.S., CRC
Biofeedback Therapy

July 31, 1979

Larry G. Stewart, Ed. D., Director
Model Demonstration Project
The Rehabilitation Center
University of Arizona
Tucson, Arizona 85721

Dear Larry:

I am pleased to have the opportunity to respond to your letter requesting my perceptions on the impact of the Model Demonstration Project in Arizona in the past three years.

I believe the project staff have played a significant role in heightening the awareness of habilitation persons throughout Arizona as to the needs of the sensory impaired developmentally delayed individuals. Staff have taken an active role in assessing training needs, diagnostic needs, and coordination needs within the existing service delivery system in Arizona. The written and vocal concerns, the frequent presentations, and the constant advocacy role assumed by all staff have serve to increase sensitivity of staff within the Division of Developmental Disabilities-Mental Retardation Services to the point where new programs and services are underway to make the lives of many HIDD individuals more full.

The State of Arizona seemed to have little knowledge or awareness of the specialized needs of hearing impaired developmentally disabled persons prior to the project initiation. The Model Demonstration Project staff have served as a catalyst to activate discussions, timelines and coordination statewide to bring people serving these individuals together towards a common goal.

I hope this letter can assist you in showing the significant effect the project has had on changing attitudes towards HIDD persons in Arizona. I have appreciated the opportunity to work with the project during the past three years and hope the project can continue to impact on services in Arizona and around the country.

Thank you.

Regards,

Marsha Dunn

Marsha L. Dunn M.Ed. O.T.R.
Associates in Human Development

January 29, 1979

Dr. Larry G. Stewart, Project Director
The Rehabilitation Center
College of Education
The University of Arizona
Tucson, Arizona 85721

Dear Dr. Stewart:

I hope you will excuse the terribly long delay in responding to Ed Ober's manuscript on Legal and Constitutional Rights of Hearing Impaired Developmentally Disabled Children and Adults. If my comments are too late my sincere apologies. The document is very well researched and very well written. It is one of the best presentations of the legalistics I have ever read. It is not a product for the best seller list, but will be valuable to people who need factual information. I am getting rather tired of reading people's opinions about what the law requires rather than what this manuscript does -- reports the laws factually. I only have several minor comments to make.

First, on page 17, line 5 -- it is misleading to suggest that there was a study that reported the data referred to. Rather the data is a result of USOE reports gathered from the states. The term "study" implies that it has some legitimate research base which I think is a presumption we would not want to make.

Second, on page 21 and 22 -- I would suggest removal of the term "mainstreaming." As you know, mainstreaming is a concept that operationalizes very differently in the words of each author or in the perceptions of the public. The term "least restrictive alternative" has legal definition and is accurately reported in the text. I do not believe it is appropriate to presume that the two terms are synonomous.

On page 28, line 2 -- I would suggest the sentence be rewritten to state "whenever parents present an independent evaluation at a hearing the hearing officer must consider it in any decision....."

Please extend to Mr. Ober my congratulations for a job well done and my apologies for the inordinate delay.

Sincerely yours,

Fred Weintraub

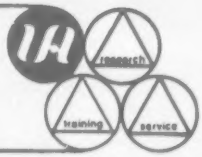
Frederick J. Weintraub
Assistant Executive Director
Governmental Relations

FJW:cww
cc: Sam Kirk

1920 ASSOCIATION DRIVE
RESTON, VIRGINIA 22091 (703) 620-3660

185

the rehabilitation center
college of education
the university of arizona
tucson, arizona · 85721



August 10, 1979

Dr. Larry G. Stewart, Project Director
Model Demonstration Program
Rehabilitation Department
College of Education
University of Arizona
Tucson, AZ 85721

Dear Larry:

To me one of the most important accomplishments of the Model Demonstration Program was to bring together people and agencies who had been peripherally interested in the Hearing Impaired Developmentally Disabled population and helping them develop meaningful programs.

This is not to overlook the importance of your other achievements such as better identification of this special population, the development of improved methods of working with these individuals, and the promotion of better public understanding of this group.

Hearing impaired developmentally disabled persons have been around for a long time although there is not question but what they are increasing in numbers. The uniqueness of their multiple handicaps usually meant they were shuttled from agency to agency. Schools for the deaf felt they did not have the knowledge to work with the additional handicaps and agencies for other handicaps did not feel they had the expertise to work with the hearing handicap. Consequently, many of these individuals fell through the cracks and became misfits in our society.

The Model Demonstration Program was able to demonstrate the feasibility of working with the hearing impaired developmentally disabled population and developed an awareness within agencies that they could work best by pooling their knowledges and skills with those from other agencies. Educational and vocational training opportunities were greatly expanded and programs became coordinated. This will have long lasting benefits. Encouraged by the improvements in programs and by the results, parents will insist that quality services be continued.

You and your staff are to be commended on a job well done, one that will have continued influence long after your project has completed its task.

Sincerely,

Armin G. Turechek, Ed.D.
Professor

fgt

186

ARIZONA DEPARTMENT OF ECONOMIC SECURITY
DIVISION OF DEVELOPMENTAL DISABILITIES AND MENTAL RETARDATION SERVICES
1400 WEST WASHINGTON • P.O. BOX 6780 • PHOENIX, ARIZONA 85005
(602) 255-5775

Bill Jamieson, Jr.
DIRECTOR

Brian Lensink
ASSISTANT DIRECTOR

August 9, 1979

Larry Stewart, Ed.D
Project Director
Model Demonstration Program
The Rehabilitation Center
College of Education, UofA
Tucson, Arizona 85721

Dear Larry:

Now that the HIDD program nears the end of its third and final year of operation, I would like to express my appreciation to you and the members of your staff for a job well done. It seems only a short time has passed since you and I first met to discuss the project in Tucson. That was, however, nearly three years ago and in the time since many worthwile contributions have been made by your program.

You and your staff have provided us with technical assistance and training throughout our six districts and have provided considerable guidance in the advancement of our services for hearing impaired clients. Additionally, we have benefited greatly from the audiological staff you have provided and from the availability of the very fine mobile testing unit. You have served, too, as a strong advocate for the needs of sensory impaired clients in our state. I know from feedback I have received that your work with community agencies and school districts has enhanced our clients ability to receive appropriate and beneficial services outside of the institutional setting.

As the program draws to a close I want you to know that it has left a significant impact on Arizona and in particular our Division. We now have established a five year goal to improve services to sensory impaired clients and many ideas and materials provided by the HIDD program are being utilized in this effort.

Thank you for your considerable efforts on behalf of our clients.

Sincerely,

Brian Lensink

Brian R. Lensink

BRL:jm

ARIZONA DEPARTMENT OF ECONOMIC SECURITY
DIVISION OF DEVELOPMENTAL DISABILITIES AND MENTAL RETARDATION SERVICES

BILL JAMIESON, JR.
DIRECTOR

DISTRICT II
P.O. BOX 13178, TUCSON, ARIZONA 85732
(602) 882-5345

BRIAN LENSINK
ASSISTANT DIRECTOR

August 9, 1979

Mr. Larry Stewart
Model Demonstration Program
The Rehabilitation Center
The University of Arizona
Tucson, Arizona 85721

Dear Larry:

Now that we near the end of the three year life of the Model Demonstration Program I would like to express my appreciation for the considerable assistance that the project has rendered to us here in Pima County.

It has been a real pleasure to have been able to provide office space for you and the other members of the program staff. We believe that our close proximity to you and your activities have most beneficial to our staff and the clients we serve.

Specifically, I would like to commend you for the technical assistance you have given to members of our Therapy Department. Your assistance has not only been helpful in specific client program planning, but has also served to point out areas in which we need to improve our overall staff training, as it relates to the needs of persons who are hearing impaired. Additionally, your assistance in establishing an audiological testing program for our clients has, I believe, greatly enhanced our ability to serve them properly.

Additionally, I know that the presence of the HIDD program in Arizona has generally heightened our awareness of the special needs of the client population in question. We now have a statewide task force within the Division of Developmental Disabilities which is advising the Assistant Director on ways in which we might improve our overall service delivery.

I am pleased to serve as the Assistant Director's personal liason to this committee and to other advocacy groups in the state with regard to these very important matters. There is no question in my mind that the HIDD program has left a significant mark on Arizona and my guess is that this is also the case in other states throughout our country.

I wish you all the best in any future endeavors you might undertake. I want you to know that I am grateful to have had the opportunity to have worked closely with you these past three years.

Best wishes,

Ronald S. Barber
Program Manager
DDD/MR Services
District II

RSB:td

ARIZONA DEPARTMENT OF ECONOMIC SECURITY
DIVISION OF DEVELOPMENTAL DISABILITIES AND MENTAL RETARDATION SERVICES
DISTRICT 9

BILL HAWKESON, JR.
Director

POST OFFICE BOX 1467 • COOLIDGE, ARIZONA 85228
(602) 723-4151

BRIAN LENSINK
Assistant Director

August 9, 1979

Larry G. Stewart, Ed. D.
Project Director
Model Demonstration Program
College of Education
University of Arizona
Tucson, Arizona 85721

Dear Dr. Stewart:

It is my pleasure to share with you my opinion of the impact which the Model Demonstration Project has achieved within the state of Arizona. I believe that the Model Demonstration Project has most significantly impacted on three major areas:

1. Prior to the Project, the hearing impaired developmentally disabled population in Arizona was, by and large, invisible. Although some significant attempts to provide services to this population had occurred in one or two areas of the state, for the most part services were nonexistent and the need for those services had not been recognized. The MDP has been responsible for a significant increase in factual data regarding this population and in increasing its visibility.

2. The Model Demonstration Project has been responsible for documenting and compiling a wealth of information relating to methods and resources for providing services to the hearing impaired developmentally disabled person. Prior to the inception of the Project, agencies providing services to this population were "re-inventing the wheel" in many cases. Methods which had been tried and found to be successful or less than successful were not available to others; publications relative to this population were almost non-existent. Project staff have sought out information from many sources and have compiled that information into useable form in their many publications.

3. Although some services were available to the HIDD population prior to the Model Demonstration Project, most professionals working with this group were unaware of the range of services available from different Agencies. In many cases, clients remained unserved or underserved simply because the professional working with the case did not know what might be provided by another agency or service organization. The Model Demonstration Project has, through multi-agency meetings, publications, and referral services, provided information which has shown which services exist throughout the state and perhaps most important, which services should be developed to provide an adequate continuum of services for the hearing impaired developmentally disabled.

My personal interaction with the Project has been extremely valuable to me, and to the Agency which I represent. I believe that the Model Demonstration Project has certainly served the purpose for which it was funded.

If I can be of further assistance, please do not hesitate to call on me.

Sincerely,

Jonna M. Miller

Jonna M. Miller
Unit III Manager

:rf

This was accomplished in part by sensitizing the professional community to the HIDD population and in part by encouraging specialized services for the HI population and the D.D. population in the form of higher quality diagnostic services. A registry of HIDD persons is currently being developed within the ongoing DDD–MR Services program.

There are the major areas where the MDP can be evaluated. However, such an assessment can take on an added dimension through the informed opinions of professionals who are in a position to observe the *end* results of the project, to say, in essence, whether work of the project "made any difference." The previous letters were solicited from individuals perceived by the project to be in a position to give an informed judgement.

SUMMARY

This chapter has attempted to present a brief "birdseye" assessment of the Model Demonstration Program.

Lacking a rigorous research design, not intended as a research project *per* se but rather as a demonstration and training project, the evaluation of the MDP must remain a general one based upon established facts and professional judgement.

The overriding purpose for the establishment of the Model Demonstration Program was to contribute to the advancement of the state of the art in serving HIDD children and adults. We of the MDP feel strongly that the project achieved this goal within the time/manpower/facility/funding constraints that were present. Time and future events with HIDD persons will be the final criterion for assessing the Model Demonstration Program.

CHAPTER 13

RECOMMENDATIONS FOR THE FUTURE

Chapters 1 through 12 have reported on the background, development, activities, achievements, and assessment of the Model Demonstration Program for Hearing Impaired Developmentally Disabled Persons. Over the course of this project of national significance, the staff gained invaluable experience from serving more than 1,000 HIDD children and adults, preparing more than 30 professional publications, and providing training to more than 3,000 school and agency personnel throughout Arizona and the nation. As the project draws to a close, it is appropriate that this experience be condensed into recommendations for the future that can be used as suggestions to guide the service, research, and training efforts of others who wish to push even further into the frontier of knowledge in serving severely handicapped persons such as the hearing impaired developmentally disabled. The recommendations that follow are offered in this spirit.

Rationale for Recommendations

Fragmentation of services for HIDD persons remains a serious, pervasive problem in all of the states studied by the Model Demonstration Program. While the project was able to help in improving coordination of services for HIDD persons to an appreciable extent, much remains to be done.

The basic problem appears to be one of a failure on the part of state and local agencies to fully recognize the seriousness and uniqueness of the needs of HIDD persons. From this comes an inability to focus upon the population, to bring existing services to bear upon these people in a more meaningful manner, and to appy the intents of existing legislation and funds in developing necessary programs for them. Too often, general service systems and schools are seen as adequately meeting the needs of HIDD persons, and there is little effort made to truly examine and respond to the special needs of these special children and adults.

That even most existing "special programs" for the handicapped are unprepared to fully meet the special needs of HIDD persons is abundantly clear. In Arizona, the majority of the 400 client/student referrals to Model Demonstration Program over an 18 month period of time came *not* from generic service and education programs (the Health Department, public schools, State Education Department, etc.) *but* from special programs (schools for the deaf, classes for the deaf in public schools, centers for the mentally retarded, special schools for the cerebral palsied, etc.).

Training and technical assistance services provided by the Model Demonstration Program to special program staff were essential to strengthening their capabilities in serving HIDD persons. In may cases this T/TA did meet the need, but in some cases even this was not enough. Special comprehensive resource centers are currently needed that simply do not exist at this time outside the Model Demonstration Program (MDP). Moreover, as the MDP is phased out of existence, there may be no catalyst to foster improved services for HIDD persons.

The Model Demonstration Program was able to assemble a staff of knowledgeable professionals from the area of the developmental disabilities and the area of hearing impairment, and, with time, to become knowledgeable concerning services for HIDD persons. Yet, the MDP staff readily acknowledges its limitations. There is a great deal more that needs to be learned about the etiology, the conditions, the treatment, the education, the rehabilitation of HIDD persons. Time, the appropriate settings, and the collaboration if many professionals from many disciplines are needed to more fully address the myriad problems and needs of HIDD children and adults. The Model Demonstration Program was able to successfully address many of these problems and needs, and to substantially impact on the state of the art. However, it must be recognized that no single project of relatively short duration can be expected to result in more than a partial response to the needs of the HIDD population.

Recommendations

1. *Services*

   a. The MDP was able to demonstrate several models of services for HIDD persons, and to show that special programming is both necessary and feasible within a variety of school and agency settings.

      It is recommended that each state include efforts to encourage the development of an array of special services for the HIDD population based upon the models described in Chapter 7. State and federal funding is available for such programming.

   b. The MDP demonstrated that the severely handicapped HIDD population requires comprehensive, specialized services over a relatively long period of time.

      It is recommended that each state establish and operate at least one comprehensive diagnostic, treatment, and education/rehabilitation center for HIDD persons.

   c. The Arizona Training Program – Coolidge Sensory Training Unit Model for HIDD persons demonstrated the need for a special unit for this population within residential programs.

It is recommended that in each state there be at least one specialized unit for HIDD persons within a state residential facility for the developmentally disabled. And, that HIDD residents be grouped for instruction and training purposes as well as for social experiences.

d. The MDP and the Community Outreach Program for the Deaf demonstrated the great need for special community residence programs for HIDD persons to assist in the deinstitutionalization process.

It is recommended that group home/independent living facilities be established for severely handicapped HIDD persons within each state, preferably one such facility at a minimum for the larger population centers. The severe communication problem justifies this departure from mainstreaming philosophy in HIDD cases where the client depends on sign language and requires specialized, long term assistance.

And, in cases where HIDD persons are housed with hearing DD persons, the staff should be required to learn and use sign language as well as be provided with training in working with HIDD persons.

Appendix contains a model for such a group home/independent living facility for HIDD persons.

e. The HIDD population is a severely handicapped, low-visibility population. There are few advocates for these children and adults. Few schools and agencies have selected them as a high priority service group.

It is recommended that State Developmental Disabilities Councils as well as Protection and Advocacy Agencies select HIDD persons as a special group to receive high priority in state level planning, protection, and advocacy activities.

f. Finally, the experience of the Model Demonstration Program indicates clearly that the relative lack of response to the needs of HIDD persons among schools and agencies is not due to a lack of funds. It is not due to a lack of "know how," nor is it truly due to a lack of information, although this is frequently a problem. The real underlying cause for the lack of response to HIDD persons is the absence of federal and state legislation that mandates, without question or "loopholes," the provision of quality, comprehensive services to these children and adults. Current legislation does not do the job. Accountability for HIDD persons is not mandated anywhere.

Accordingly, if this country is sincere in its desire to effect quality services for HIDD persons, it is recommended that categorical federal legislation be enacted calling for the establishment and operation of ongoing regional comprehensive diagnostic, education, and

rehabilitation centers for HIDD children and adults. Such legislation has a precedent in the current legislation for deaf-blind persons (National Center for Deaf-Blind Persons, regional centers for deaf-blind children). The HIDD population certainly has among its members a large proportion having problems as severe as those for the deaf-blind. Currently, the absence of such legislation has created conditions where many HIDD persons spend their lives in public institutions, merely "cared for" rather than rehabilitated and deinstitutionalized, at an annual cost that ranges from $12,000 to $60,000 per year. The cost in dollars, in wasted human potential, and in individual hopelessness and despair is far too great to be allowed to continue. Mandated services offer the only hope for reversing this long-established set of conditions that even today continues to rob tens of thousands of HIDD persons of the quality of life that they deserve and to which, under the Constitution of this nation, they are entitled.

2. *Research and Training*

   a. There are countless schools and agencies that *do* serve HIDD persons, regardless of the fact that they are not well prepared to do so. This practice will continue unless efforts are made to prepare practicing professionals and paraprofessionals to do a better job.

      It is recommended that federal program planners ensure that the current training and technical assistance (T/TA) activities of the Model Demonstration Program are continued beyond the life of the current MDP project grant which expires 9/30/79. These T/TA services will continue to be urgently needed. Although the MDP will reach the goals set for it by 9/30/79, much dissemination of its findings via future workshops, conferences, and training sessions remains to be done. Continuing efforts for T/TA activities in the HIDD area are needed via one or more of the following:

      1. *Continuation of MDP-initiated activities through selected University Affiliated Facilities.*

      2. *New HIDD T/TA services via a site or sites selected by the government.*

      3. *Continuation of the current MDP activities through the University of Arizona.*

   b. Although the MDP has compiled much important information about the HIDD population, much more needs to be learned about these children and adults.

      Accordingly, it is recommended that:

1. *The Federal Bureau of Developmental Disabilities (HEW) encourage the Gallaudet College Office of Demographic Studies and the UCLA/NPI IDB system to undertake on-going demographic studies of the HIDD population.*

2. *The individual D.D. State Plans (mandated by P.L. 94-103) should require attention to the reporting of HIDD population statistics. These statistics should then be used in planning future services.*

c. There continue to be service areas where there is insufficient information about the HIDD population. Support is needed for longitudinal research in such areas as prevention, early identification, education, treatment, and rehabilitation.

It is recommended that the Bureau of Developmental Disabilities, the Bureau of Education for the Handicapped, and the Rehabilitation Research Institute vigorously pursue the funding of a laboratory type center, perhaps within a selected University Affiliated Facility, designed to advance the state of art in serving HIDD persons over the next decade.

In selecting future sites for service, research, and training activities in the HIDD area, funding agencies such as HEW should consider only appropriate settings that offer the kinds of interdisciplinary support services that are basic to an attack on the problems of HIDD persons. An effective center for the study of HIDD persons, in order to fulfill its mission, can be most successful if it is located within, and receives full administrative support from a sponsoring institution having goals that are compatible with the HIDD center goals.

Through such activities, HIDD persons will *begin* to receive the kinds of assistance that they need and deserve.

APPENDIX I

MODEL DEMONSTRATION PROGRAM HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS

The Rehabilitation Center
College of Education
Tucson, Arizona 85721

Service Program Questionnaire

NAME OF INTERVIEWER: _____ Date of Interview: ____

Agency Contact Person: _____ Title: _____

1. Name of agency: _____
2. Address of agency: _____ Zip Code: ____
3. Telephone number(s): _____
4. Chief Administrator: _____
5. Agency is supported by: _____

__State __City __County __ Other (Specify: _____)

6. Annual budget (1976-77): _____

	Pre School			School Age			Adult				Cost to Client
	HI	DD	HIDD	HI	DD	HIDD	HI	DD	HIDD	Category	
A.										Information and Referral	
B.										Audiological screening	
C.										Audiological assessment (in-depth)	
D.										Speech and hearing services	
E.										Manual communication instruction	
F.										Medical assessment	
G.										Medical treatment (Nature: _____)	
H.										Educational assessment	
I.										Psychological assessment	
J.										Counseling	
K.										Parent education	
L.										Parent counseling	
M.										Occupational therapy	
N.										Physical therapy	
O.										Recreation	
P.										Personal care	
Q.										Transportation	
R.										Activities of daily living	
S.										Supervised community living	
U.										Day care	
V.										Education	
W.										Training	
X.										Vocational training	
Y.										Sheltered workshop	
Z.										Protective/Legal	

7. Professional staff:

Full-Time	Part-Time	Total Staff		Position	Referral Out Only
____	____	____	A.	Audiologist (C.C.C.)	____
____	____	____	B.	Speech Specialist (C.C.C.)	____
____	____	____	C.	Aural Rehab. Specialist (C.C.C.)	____
____	____	____	D.	Physical Therapist	____
____	____	____	E.	Occupational Therapist	____
____	____	____	F.	Counselor (B.A.)	____
____	____	____	G.	Counselor (M.A.)	____
____	____	____	H.	Psychometrist (B.A.)	____
____	____	____	I.	Psychologist (PH.D.)	____
____	____	____	J.	Teacher (B.A.)	____
____	____	____	K.	Teacher (M.A.)	____
____	____	____	L.	Recreation Specialist	____
____	____	____	M.	Nurse (R.N.)	____
____	____	____	N.	Nurse (L.P.N.)	____
____	____	____	O.	Medical Doctor	____
____	____	____	P.	Other	____

8. Number of H.I.D.D. Clients served:

____ A. Total for year 1975-76

B. Total current H.I.D.D. ci

____ 1) Resident

____ 2) Day

9. Would you be interested in receiving a newsletter regarding the progress of the Project? ____

10. Would you be interested in a copy of the Services Directory? ____

11. COMMENTS:

MODEL DEMONSTRATION PROGRAM
THE REHABILITATION CENTER
COLLEGE OF EDUCATION
THE UNIVERSITY OF ARIZONA
TUCSON, ARIZONA 85721
(602) 626-2701

Gentlemen:

The Model Demonstration Program at the University of Arizona has recently completed its second full year of operation. Our task of investigating the organization of programs for persons who are hearing impaired and developmentally disabled (HIDD) is completed, and we are prepared to share our findings with schools and agencies throughout the United States.

One of the ways that we feel we can best serve this purpose is through a no-cost analysis of the services currently offered to HIDD persons and a subsequent set of recommendations designed to enhance programming efforts. The Model Demonstration Program exists to offer training and technical assistance to service providers, and it is our contention that we must do so with an emphasis on the needs of the client and the capability of an agency to meet those needs.

In this regard, we should like to extend an invitation to you to participate in the Model Demonstration Program's "Analysis of Services." This involves the completion of documentation of your current program efforts and a site visit by a member of our staff after we have designed recommendations based upon your input. These recommendations will focus on the HIDD population and includes specific program components, materials lists, and organizational suggestions. Naturally, it remains the prerogative of the agency to use, modify, or ignore any or all of these recommendations. In addition, we are prepared to develop specific training modules for your school or agency based upon the outcome of the analysis. The accompanying flow chart is designed to clarify the analysis procedure.

We hope that you will consider participating in our Analysis of Services by returning the attached information survey. Through your cooperation with this effort, we can assure the provision of improved services to persons who are hearing impaired and developmentally disabled.

Sincerely,

Joseph B. Perine
Assistant Director for Services

JBP/jt
Enclosure

APPENDIX
Program Analysis
VIF and Associated Correspondence

Information Survey

Name of School/Agency _____

Address _____

_____

Telephone _____

Name of Contact Person _____

Title/Position _____

Phone _____

Date _____

EMPHASIS OF AGENCY

- Program Implementation _____
- Advocacy _____
- Counseling _____
- Diagnosis _____
- Research _____

AREA OF EMPHASIS

- Hearing Impairment _____
- Autism _____
- Cerebral Palsy _____
- Epilepsy _____
- Mental Retardation _____
- Other (Specify) _____

Other Remarks/Information _____

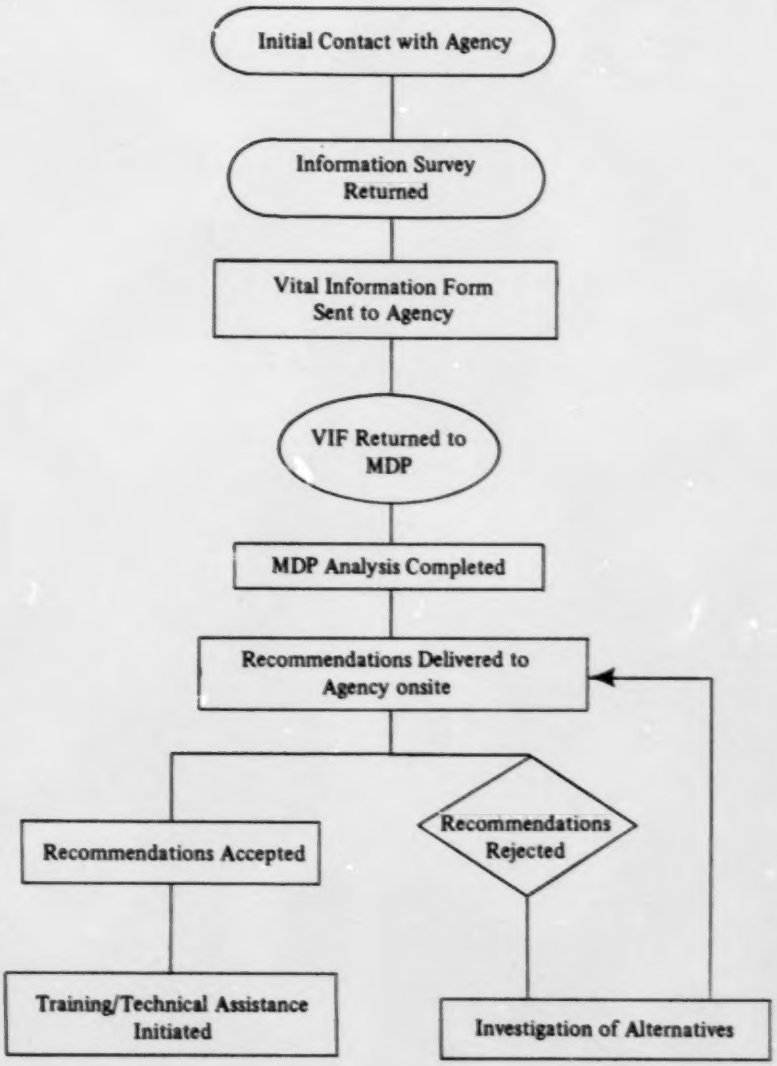
_____

_____

_____

Analysis of Services

Flow Chart



200

MODEL DEMONSTRATION PROGRAM
THE REHABILITATION CENTER
COLLEGE OF EDUCATION
THE UNIVERSITY OF ARIZONA
TUCSON, ARIZONA 85721
(602) 626-2701

Dear Colleague:

Thank you for your willingness to participate in the Model Demonstration Program's "Analysis of Services." We are certain that with your cooperation, the state of the art in serving persons who are hearing impaired and developmentally disabled can be improved.

The enclosed "Vital Information Form" (VIF) should be completed by a member(s) of your administrative/supervisory staff and returned to us as soon as it is convenient. After we have reviewed the VIF, we will develop a series of needs-based recommendations with direct reference to your input. These recommendations will then be presented to you either in a written communication, or during a personal visitation to your facility. Your choice of methods should be stated in a letter accompanying the VIF when you return it to us.

Again, thank you for your participation in this program, and if there is any other way in which we can be of service to you, please do not hesitate to call on us.

Sincerely,

Joseph B. Perine
Assistant Director for Services

JBP/mc

Enclosure

201

Analysis of Services
to
Hearing Impaired Developmentally Disabled Persons

VITAL INFORMATION FORM

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APPENDIX II

VIF and Associated Correspondence

INTRODUCTION

This document is an initial effort at developing an instrument by which services to hearing impaired developmentally disabled (HIDD) persons can be analyzed. Neither the instrument nor the process is in finished form; instead both components will be modified as the document is used in pilot studies. These studies will be undertaken by the staff of the Model Demonstration Program (MDP) in cooperation with the personnel of various schools and agencies throughout Arizona. Feedback from MDP staff members and cooperating school and agency personnel will serve as the basis for developing training materials to accompany the analysis tool, as well as contributing to the modification of the instrument itself.

The principal purpose of the instrument will be the formative analysis of programs serving HIDD persons. As such, the instrument will be used to provide program personnel with information by which they can improve the services they are providing. Data will be gathered during the pilot stages of the analysis which will contribute to the establishment of standards for service in various settings, and once these standards have been established, it will be possible to conduct analysis in accordance with a currently existing evaluation model, specifically, that of Robert Stake (1967).

The analysis model presented in this document may also be used summatively. This purpose is, however, secondary to the formative purpose for which the system was designed. Guidelines for using this instrument to conduct a summative or formal assessment will be developed at a later date.

During the pilot stage staff members of the cooperating school or agency, the services of which are being analyzed, will serve as informants. In this role, only a minimal amount of their time will be necessary. Service providers will supply the information requested in the document, and then forward it to the MDP. The staff of the Model Demonstration Program will synthesize the data and report it back to the chief administrator of the participating agency via an onsite visit. The report will include a summary statement of the service system and a series of recommendations where such are deemed necessary and appropriate. During the pilot phase, the results of the analysis will be made available only to the staff of the cooperating school or agency, and to MDP staff members on a need-to-know basis.

Again, it is important to remember that this information is to be used to improve services where improvement is needed. Voluntary participation in this process is a sign of willingness to look closely at a service system, with a focus on providing success-oriented programs for persons who are hearing impaired and developmentally disabled.

School or agency _____

Address _____

_____

_____

Phone _____

Individual(s) completing Vital Information Form

Name	Position	Date(s)

PROGRAM ANTECEDENTS

Instructions

Items 1 through 9 of this portion of the analysis are general questions concerning the nature of the school or agency. To complete these items, input from other staff members may be requested, or program documents may be consulted in order to supplement individual experience. There is no need to respond to these items in great detail; they are merely intended to provide an overview of the adherence factors on which a school or agency is based.

The remaining items that fall under the heading of "antecedents" are essential to the success of the analysis, and should be answered carefully and thoroughly. As was the case with other items in this section of the document, staff input or program documents can serve as the supplementary data sources for these items. Be sure to follow the guidelines associated with each item, since adherance to these guidelines will result in uniform and complete responses. The guidelines follow each item and are enclosed in parentheses.

Please keep in mind that the information supplied in this section is the first step towards an improved service program.

1. Briefly describe the purpose of your organization.

2. Describe the physical plant with respect to the following characteristics: 1) general appearance, 2) space, 3) accessibility, 4) maintenance, 5) equipment, 6) ventilation. This description should focus on the quality of each of the characteristics.

3. What specific provisions have been made to adapt the physical plant to the health, communication, and safety needs of hearing impaired developmentally disabled (HIDD) persons?

4. Identify the formal relationships that the school or agency maintains with other schools or agencies on behalf of HIDD clients. These relationships should be stated as a specific policy, result from a contractual agreement, etc.

School or agency	Description of relationships

5. Describe any informal relationships that the school or agency maintains with other schools or agencies such as access to consultative services, use of information resources, etc.

6. What relationship exists between the school or agency and organizations of and for hearing impaired persons, cerebral palsied persons, autistic persons, mentally retarded persons?

7. What is the *funding base* for the school or agency?

8. Describe any difficulties encountered in obtaining funds to serve HIDD persons. (Include funding limitations, inter-agency communication problems, lack of coordination, lack of clear responsibility, or problems specific to a school or agency).

9. Does the school or agency have an advisory board?_____ If so, what is its composition, and is there a mechanism for consumer input from HIDD persons or their advocates?

10. Describe the characteristics of the HIDD clients served by the school or agency.

10.1 *Number* (Include the number of HIDD persons being served and the total client population)

HIDD_____ TOTAL_____

10.2 Age distribution (Respond to this question by indicating the number or percentage of HIDD clients in each age range. If this information is unavailable, simply indicate the number of children and adults)

0 - 5 _____
6 - 12 _____
13 - 18 _____
19 - 59 _____
60 and above _____

OR

Children (0-18) _____
Adults (19-up) _____

10.3 **Handicapping Conditions**	**Number of Percentage**
Hearing Impaired Mentally Retarded	_____
Hearing Impaired Autistic	_____
Hearing Impaired Cerebral Palsied	_____
Hearing Impaired Epileptic	_____
Hearing Impaired Mentally Retarded/ Austic	_____
Hearing Impaired Mentally Retarded/ Cerebral Palsied	_____
Hearing Impaired Mentally Retarded/ Epileptic	_____
Hearing Impaired Mentally Retarded/ Autistic/Cerebral Palsied	_____
Hearing Impaired Mentally Retarded/ Autistic/Epileptic	_____
Hearing Impaired Mentally Retarded/ Cerebral Palsied/Epileptic	_____
Hearing Impaired Mentally Retarded/ Autistic/Cerebral Palsied/Epileptic	_____
Hearing Impaired Autistic/Cerebral Palsied	_____
Hearing Impaired Autistic/Epileptic	_____
Hearing Impaired Cerebral Palsied/Epileptic	_____

10.4 Racial/ethnic composition	**Number of Percentage**
Caucasion	_____
Native American	_____
Black	_____
Hispanic	_____
Oriental	_____
Other/mixed	_____

10.5 *Average length of time service is rendered* (in months) _____

10.6 Average cost of serving an HIDD client. _____

10.7 Average cost of serving non-HIDD client. _____

10.8 Indicate any other characteristics that may be of interest, such as financial status of clients or their families, religious affiliation necessary for service, parental or family status, etc.

10.9 Indicate the difficulty associated with retrieving the information relating to items 10.1 through 10.7. Was it readily accessible, or was a great deal of effort necessary to obtain it?

11. Describe the characteristics of the professional staff of the school or agency.

11.1 Total professional staff (including administrators) _____

11.2 *Specializations* (include administrators)

Area of Specialization	Number or Percentage	Professional Certification

11.3 *In service training opportunities*

11.4 *Continuing education opportunities*

11.5 **Racial/Ethnic composition**	**Number of Percentage**
Caucasion	_____
Native American	_____
Black	_____
Hispanic	_____
Oriental	_____
Other/mixed	_____

11.6 Identify staff positions held by disabled persons.

11.7 Describe the turnover rate of the staff in each area of specialization (precise figures, though helpful, are not absolutely necessary, approximate percentages are acceptable)

11.8 Describe any other relevant staff characteristics that may contribute to analyzing the services of the school or agency.

12. Describe briefly the administrative structure of the school or agency. (Include a chart of organization/operation if possible.)

13. Additional comments or information.

PROGRAM TRANSACTIONS

Instructions

This portion of the analysis is one of the most essential, but is also one that is comparatively difficult to complete. Two factors contribute to the difficulty related to obtaining information on program transactions. First, in addition to staff input and document reviews, the data sources for this portion include extensive observations. A second factor is the magnitude of the undertaking; some programs comprise so many activities that evaluating each one will be very time consuming. As a consequence of these factors, a great deal of effort will go into gathering the data pertaining to program transactions.

In obtaining the data pertaining to program transactions, it is important to record what actually exists. Therefore, attempt to corroborate the statements made by other informants and the information obtained from program documents with individual observations of program transactions, and document any discrepancies among these data sources. Discrepancies related to each item should be indicated at the conclusion of the response to each item.

This portion of the analysis is of tremendous importance in developing recommendations in a realistic context. Improving client progress is, quite often, a matter of altering the transactions within a system in order to align them more closely with client needs.

Program Transactions

1. Listed on the following pages are services that are often provided to HIDD persons. Identify those services provided by the school or agency, and answer the questions on the following pages as they relate to that particular service.

    1.1 Are there services offered to non-HIDD persons that are not offered to HIDD persons?_____ Indicate which services they are, and why they are not offered to HIDD persons.

Answer the following questons as they relate to the general delivery system of the school or agency. *Note any discrepancies between services offered to HIDD persons and those offered to non-hearing impaired clients.*

2. How does the school or agency determine whether or not its services are provided in the "least restrictive environment"?

3. Does it appear as if HIDD persons are being served in the least restrictive environment?_____ If not, discuss briefly why services are not offered in this way.

4. Does the school or agency cluster HIDD persons together or are they dispersed throughout the general client population? Discuss briefly the rationale for this choice.

5. Describe the due process procedures available to HIDD persons.

6. What are the precautions taken to guarantee the confidentiality of HIDD clients' records?

7. Attach a copy of the individual habilitation or education plan for one client and return it with your evaluation. Please be sure to delete all identification.

   7.1 Does this plan serve as the basis for treating or educating HIDD clients? ____ (yes or no)

   7.2 Is an individual plan available for each HIDD client? ____ (yes or no)

8. Are specialized materials and resources available for HIDD clients?____ (yes or no)

9. How is the progress of HIDD clients monitored?

10. Describe the nature of the communication that exists between HIDD clients and the staff of the school or agency.

    Oral Communication _____
    Manual Communication _____
    Total Communication _____
    Other (Specify) _____
    _____

11. Describe the opportunities for and quality of interaction between HIDD clients and persons outside the agency.

12. How is information pertaining to your school or agency made available to consumers, parents, and/or advocates of HIDD persons?

13. What process is used to refer HIDD clients to your school or agency?

14. List the sources of referrals of HIDD persons to your school or agency.

15. How do other schools or agencies monitor HIDD referrals to your school or agency? Basically, how do these schools or agencies find out if you are doing your job?

16. What process do you use to refer HIDD persons to other schools or agencies?

17. List the places to which you refer HIDD clients.

18. How do you monitor HIDD referrals to other schools or agencies?

19. How are services to HIDD persons coordinated within your school or agency?

20. Additional comments pertaining to program transactions.

PROGRAM OUTCOMES

Instructions

This portion of the Analysis of Services–Vital Information Form provides the opportunity to describe the outcomes of your agency's attempts to serve the HIDD population. Regardless of the nature of the outcomes, it is worth noting that an organization that serves, attempts to serve, or is willing to serve this group of individuals is moving forward in the human services area.

The recommendations resulting from this analysis will attempt to help create, modify, or reinforce current services to persons who are hearing impaired and developmentally disabled.

1. What *subjective* criteria are available by which client progress can be assessed?

2. According to these criteria, the performance of what percentages of HIDD clients:
   Improved _____
   Remained the same _____
   Regressed _____

3. How easy was it to obtain this information? (Check one)
   No problem _____
   Relatively easy _____
   Fairly difficult _____
   Very difficult _____
   Impossible _____

4. Select an HIDD client at random, and using the subjective and objective criteria described previously, summarize the changes in that client's behavior since that client entered the school or agency.

5. What materials, publications, etc. are produced by your school or agency regarding HIDD clients and made available to the professional community? Include copies where available.

6. Is cost/benefit information available concerning the services offered by your school or agency to HIDD persons?_____If so, summarize this information,

and indicate if there is a discrepancy between this information as it pertains to HIDD clients and the same information on non-hearing impaired clients.

7. In the space below, indicate the percentage of HIDD clients that enter each setting as they complete the program being offered by your school or agency.

Residential

Natural or adoptive parents	_____
Foster parents	_____
Institution for the mentally retarded	_____
Residential school for the hearing impaired	_____
Group home	_____
Supervised apartment	_____
Independent living	_____
Other (Specify) _____	_____

Vocational or educational

Competitive employment	_____
Adult workshop	_____
Vocational training/evaluation center	_____
Institution for the mentally retarded	_____
Residential school for the hearing impaired	_____
State hospital	_____
Public school	_____
Other (Specify) _____	_____
None	_____

8. What percentage of HIDD clients leave your school or agency but eventually return? ____ How does this compare with the same figure for non-hearing impaired clients?

9. What percentage of HIDD clients were deinstitutionalized or mainstreamed last year?_____ What percentage do you expect will be deinstitutionalized or mainstreamed this year?_____

10. Additional comments as they pertain to program outcomes.

SUMMARY

You have just completed a rigorous review of your program as it relates to persons who are hearing impaired and developmentally disabled (HIDD). The information that you have supplied to the Model Demonstration Program will serve as the basis for a series of needs-based recommendations designed to improve programs for the HIDD population currently being served by your organization.

211

These recommendations will be presented to you during an onsite visitation to your school/agency at which time an MDP staff member will discuss the information at length. At that time, we should also appreciate your candid assessment of this Analysis of Services including such things as 1) time needed to complete Vital Information Form, 2) ease of completing Vital Information Form, 3) value of a visit by the MDP, and 4) the value of the outcomes of the analysis. If you have additional comments at that time, they will be welcomed.

Thank you for your cooperation with this effort on behalf of every person who is hearing impaired and developmentally disabled.

APPENDIX III

COMMUNITY OUTREACH PROGRAM FOR THE DEAF GROUP HOME

EXHIBIT "I"

A. Program Description

1. Name: Community Outreach Program for the Deaf
   Location: 3200 North Los Altos Avenue, Tucson, Arizona 85705
   Telephone: 623-0344, ext. 266
   Contact persons: Roger Beach/Peggy Harmon

2. Services to be provided under this contract

   a. As defined by the Arizona Department of Economic Security/Rehabilitation Services Bureau:

      "Sheltered Residential Living – will provide a milieu of those services which will enable the individual to maintain himself at a maximum level of independence. Sheltered residential living is provided only in concurrence with other rehabilitation services. It is normally provided outside working hours and must include the following minimum components: meals, housing, crisis intervention, personal counseling, home management skills, and personal and social adjustment. In addition, it may include transportation as well as other services."

   b. As further defined by the Agency

      i. Supervision of all residents during the hours of 4:00 pm to 8:00 am, daily.

      ii. Instruction in activities of daily living to include:

         a) money management
         b) communication
         c) personal hygiene
         d) mobility
         e) housekeeping
         f) purchase and preparation of food
         g) alternative use of leisure time

3. Purposes, Goals and Objectives

a. Agency Purpose

COPD is dedicated to providing a broad spectrum of direct client services which result in maximizing the hearing impaired person's full integration into the community. As COPD pursues this general direction, we see the agency augmenting and complementing existing services available to deaf clients through both DES/VR and MDP.

The "Group Home/Sheltered Residential Living" component of the agency is viewed as the fundamental supportive service in the existing network of COPD services, as outlined on page 1a. It is from the instruction (accomplishment) in the activities of daily living that the client/resident can then involve him/herself in the educational training phases of his/her Individual Written Rehabilitation Plan.

b. Goals

The resident will be assisted, through educational and counseling techniques in:

1.0 Developing competencies in the various skill areas of independent living, specifically:

1.0.1 – Money Management/Shopping
1.0.2 – Communication
1.0.3 – Purchase and Preparation of Food
1.0.4 – Personal Hygiene and Health Care
1.0.5 – Mobility
1.0.6 – Housekeeping
1.0.7 – Alternative uses of leisure time
1.0.8 – Social Integration and Interaction

c. Objectives

1.0.1 – The resident will develop and be able to demonstrate improvement in his/her ability to:

1.0.1.1 – Identify and manage money (math skills)
1.0.1.2 – Make appropriate judgements in the utilization of money
1.0.1.3 – Understand and use checking and saving accounts in combination

1.0.2 – The resident will be better able to communicate effectively in situations requiring communication via:

1.0.2.1 – Written means (i.e., by hand or TTY)
1.0.2.2 – Total Communication

1.0.3 – The resident will demonstrate his/her ability to care for his/her personal hygiene in a manner acceptable to peers and public standards

1.0.4 – The resident will develop an individualized transportation system, through the instruction and where necessary the actual accompaniment of the supervisor.

1.0.4.1 – Where appropriate, instruction and assistance will be provided in acquiring the skills necessary to complete the written Arizona driver's license exam.
1.0.4.2 – Instruction in the use of maps in order to permit travel by either bike or foot.

1.0.5 – The resident demonstrate his ability to maintain his/her private quarters and commonly shared apace in a manner acceptable to his/her roommate and/or supervisor.

1.0.6 – The client will be able to plan, purchase and prepare meals of balanced nutrition. Purchase of food items will be made using foodstamps.

1.0.7 – The student will involve him/herself in a variety of alternative social and recreational activities during his/her leisure time.

C. Program of Services

1. Intake

2. Individualized Program Plan refer to pages 232 and 233.

3. Services

a. Requirements for admission:

i. The resident be involved in a full time training or work activity outside the center between the hours of 8:00 am – 4:00 pm, M – F.

ii. The resident be a referral from either the MDP for DES/VR or the City of Tucson and be funded for these services.

b. Proposed Daily Schedule

i. Monday thru Friday

215

5:30 am – Wake Up
6:00 am – Make up private quarters
6:15 – 6:45 am – Breakfast
6:45 – 7:15 am – Departure for training; school; job; work experience, etc.
8:00 am – 4:00 pm – No residents are to be at the center except in the case of illness
4:00 – 5:00 pm – Return to center
5:00 – 6:00 pm – Preparation of evening meal
6:00 – 6:45 pm – Evening meal
6:45 – 7:15 pm – Clean up from meal
7:30 – 9:00 pm – M, T, and TH – Group instruction in activities of daily living
9:00 – 10:00 pm – FREE
10:00 pm – Sunday – TH, curfew
10:30 pm – Lights out

ii. Wednesday – 7:00 9:00 pm, structured recreational activity (participation is optional)

iii. Curfew for Friday & Saturday is 12:30 am

iv. Weekend schedule – pending

4. Progress Reports – will be prepared by the COPD Group Home Supervisor monthly and forwarded to the referring agency during the first week of each month.

Position: GROUP HOME SUPERVISOR (for Deaf Individuals)

Payscale: Single Individual $6,000 – $8,000/year
(plus $50/month for food stipend)

Married Couple $8,000 – $10,000/year
(plus $100/month for food stipend)

Duration of Employment: August 1, 1977 – June 30, 1978

Hours of Employment: Monday – Friday, 4:00 pm – 8:00 am plus one weekend/month (three weekends off)

EXAMPLES OF DUTIES:

1) Assessment of each residents' functional level at time of entry into the program, according to the "Independent Living Skills Inventory".

2) Development of an individual program plan for each resident.

3) Instruction of group daily living skills classes during the evening hours, 7:00 to 9:00 pm.

4) On a monthly basis, monitor residents' progress in each resident's plan.

5) Supervision of all activities either at the Group Home or related hands-on experiences in the community (i.e. shopping, riding the bus to evening recreational activities, etc.) between the hours of 4:00 pm – 8:00 am, Monday thru Friday. Note the attached copy of the proposed daily schedule.

6) Supervision and instruction of residents in the preparation of meals and have meals with them.

7) Writes monthly reports on the progress of each resident and forwards to the appropriate referring agency counselor.

MINIMUM QUALIFICATIONS:

1) Advanced level manual communication skills (sign language)

2) Bachelor's degree in social science or related field.

INTRODUCTION

The purpose of assessment is primarily to establish a starting point for plan development. The materials contained in this packet are to be used in both deciding which are the deficit areas and what are the goals in achieving competance in these areas. The steps in the assessment include:

1. Review all past records in order to obtain a general idea concerning the functioning level of the client. This is important because it will save time when the assessment process begins.

2. Administer the assessment items.

3. Summarize the results on the summary page.

4. Develop individualized plan, which sets priority on needs in the critical areas.

The assessment of independent living skills for each person should not be considered a single time activity. It is a continual process that includes change as improvement occurs. The plan will include weekly progress checks and monthly progress summaries. These should be used to track movement towards goals, document need for additional instruction if improvement is slower than anticipated and to provide a final plan for exit.

Remember that all information concerning a client is confidential and to be used only in professional communication.

INSTRUCTIONS FOR ADMINISTRATION

Please review these instructions carefully and the entire package prior to beginning the assessment. Be aware that the functional areas are independent and that it is incorrect to assume that low achievement in one area will mean the same level in another area. Familiarity with the client's background is most important since it will indicate the starting point for item administration. Validate impressions with information from other sources (counselors, work supervisors, teachers); this will increase the accuracy of the report.

1. Administer ABLE according to the test instructions.
2. Begin each section with the item which is an estimate of the functioning level of the client. (Example: In the section on banking, if the person has a savings account, it is not necessary to question him concerning the items involving lower level skills.
3. If the starting item is failed, move to each successive lower item until one is passed.
4. If the starting item is passed, continue with each successive higher item until one is failed.
5. Circle the highest item passed.
6. Some of the skill areas will require observation of the client in a particular setting. The first ten days of residence should be considered observation time and the assessment completed upon the tenth day.
7. When assessment is complete write the summary of results.
8. Review summary of results with the counselor.
9. When the review is complete write a plan for each deficit area including suggested activities.
10. Write individualized program which includes a summary of all deficit areas and projected goals to exit.
11. Begin weekly check sheet.

INDEPENDENT LIVING SKILLS INVENTORY

I. Math Skills

IA. Administer ABLE – Math Section

Circle highest level applicable for each item.

IB. Identification and Mathematical Mechanics of Money

0. Individual displays no ability to distinguish coins or paper money from other objects.

1. Individual can isolate coins from a group of objects containing coins and non-coins.

2. Individual can isolate similar coins from a group of mixed coins.

3. Individual can correctly select coin when given word and/or manual sign for "one cent" or "one penny" and can communicate word and/or manual sign for "one cent" or "one penny" when shown coin.

4. Individual can correctly select coins when given words and/or manual signs for "one cent" or "one penny," "five cents" or "one nickel" and can communicate words and/or manual signs for these coins when shown coins.

5. Individual can correctly select coins when given words and/or manual signs for all of the above plus word and/or manual sign for "ten cents" or "one dime" and can communicate words and/or signs for all of these coins when shown coins.

6. Individual can correctly select coins when given words and/or manual signs for all the above plus word and/or manual sign for "twenty-five cents" or "one quarter" and can communicate words and/or signs for all of these coins when shown coins.

7. Individual can correctly identify various paper bills.

8. Individual can select coins for purchases up to five cents utilizing pennies or nickel alone.

9. Individual can select coins for any purchases up to ten cents using combinations of nickels and/or pennies or dime.

10. Individual can select coins for any purchase amount up to twenty-five cents.

11. Individual can select coins for any purchase amount up to one dollar.

12. Individual can select appropriate bills for any whole dollar amounts up to ten dollars.

13. Individual can select bills and change for any purchase amounts up to ten dollars.

14. Individual can select appropriate combinations of coins and bills for purchases of ten dollars or greater.

IC. Functions of Money

0. Individual displays no understanding of the value of money as a medium of exchange.

1. Individual works for weekly monetary reward.

2. Individual recognizes a paycheck as payment for work.

3. When purchasing an item, individual waits for change.

4. Individual will save some money for use at a future date.

5. Individual can cash a paycheck, save a portion of money, and spend the rest.

ID. Judgements in Utilizing Money

0. Individual does not understand the concept of "more than" as applied to money.

1. Individual displays understanding of the concept, "more than." (ex: $5 *is more than* $1.)

2. Individual displays understanding of the concept, "less than." (ex: 25¢ *is less than* $1.)

3. Individual can view two similar articles and distinguish differences in price.

4. Individual can make weekly budget that reflects his needs.

5. Individual spends money according to a planned budget amount. (ex: student has choice between two items, one listed on budget, the other not; selection is based upon the written budget.)

6. Individual saves money for expensive items over many pay periods in order to obtain the item which is not necessary for basic daily living.

IE. Banking

0. Individual does not know location or function of a bank.

1. Individual displays superficial understanding of function of a bank and can specify location of one bank.

2. Individual has a savings account and uses it correctly.

3. Individual has both checking and savings accounts and uses them correctly.

4. Individual has borrowed money and is engaged in repayment procedure.

5. Individual has credit cards and maintains budgeted payments.

II. Reading Skills

IIA. Administer ABLE

IIB. Ability to Follow Instructions

0. Cannot follow instructions no matter how they are communicated.

1. Can follow a physical demonstration.

2. Can follow signed/verbal instructions with a physical demonstration.

3. Can follow simple signed/verbal instructions without physical demonstration.

4. Can follow complex signed/verbal instructions without physical demonstration.

5. Can follow simple written instructions. (ex: cookbook).

III. Vocational Attitude

IIIA. Independent attendance: Leaving for work

0. Cannot or will not prepare to leave for work.

1. Is ready to leave for work with considerable or less than considerable assistance or prompting.

2. Is ready to leave for work with minimal or no assistance or prompting.

3. Is ready to leave for work with no assistance or prompting.

IIIB. Attitude Towards Attending Work

0. Shows no willingness to go to work.

1. Demonstrates at least some willingness to go to work.

2. Demonstrates interest in going to work.

3. Shows eagerness to go to work.

IV. A. Community Utilization Skills

0. Client's behavior does not allow him economic and/or social contact with the community.

1. Client's behavior allows participation in community related trips; tasks may have to be done for him. (ex: might not do own shopping except under total supervision.)

2. Client can utilize community facilities with direct supervision. (ex: uses community facilities such as YMCA or bowling alley but needs close supervision by staff.)

3. Client can utilize community facilities with minimal supervision. (ex: can do own shopping but may need help at check-out.)

4. Client can function and utilize facilities in the community unsupervised. (ex: walks to theatre, buys ticket, sees movie, returns to living area when finished.)

IVB. Language in the Community

0. Language development inadequate for community concepts.

1. Is able to receptively attach meaning to community activity through words or signs (bowling, swimming, movie, etc.).

2. When in community, client can follow signed or spoken language directions to utilize community resources. (ex: "Go to toilet," "pay the clerk," "line up here," "which shirt do you want?")

3. When in the community, client is able to expressively identify various community resources. (ex: when passing by a community resource, can say or sign "store," "bank," "park," "house," etc.)

4. Client can expressively communicate his thoughts about the community resources that he utilizes.

IVC. Effectiveness of Communication in Community

0. Client relies entirely on staff to communicate his needs.

1. Client can independently acquire basic commodities without use of language.

2. Client can receive spoken directions or visual clues from community agent and respond accordingly. (ex: when at a food store, the clerk asks for payment at the check-out, client produces money.)

3. Client can expressively convey communication of needs to a community agent. (ex: client needs flashlight batteries; he brings battery or flashlight with him to the store and shows clerk.)

4. Client can understand a community agent's spoken directions or questions in order to accomplish a community activity with little or no frustration to himself or community agent.

5. Client utilizes language skill while in the community so that he is understood by most community agents.

V. A. Personal Hygiene

0. Individual is not capable of maintaining own hygiene even under very close supervision and prompting.

1. Individual maintains personal hygiene with very close or less than very close supervision and prompting; may have some unacceptable hygienic mannerisms. (e.g., too much perfume, too much powder, washes hands too often, uses deodorant on entire body, etc.)

2. Individual maintains personal hygiene with a moderate amount or less than moderate amount of supervisions; may have some unacceptable hygienic manherisms.

3. Client maintains acceptable hygiene with little or minimal supervision. (ex: bathes adequately and readily when needed, brushes teeth, changes underclothing, etc.)

4. Individual independently maintains adequate personal hygiene.

VB. Room Cleaning Skills

0. Does not clean own room or area even with direct supervision and help.

1. Cleans own room or area with direct or less than direct supervision and help.

2. Cleans own room with a moderate or less than moderate amount of supervision and help.

3. Cleans own room with minimal or no supervision; may need to be checked when completed.

4. Cleans room independently and thoroughly as the need arises.

VC. Care of Personal Belongings

0. Assumes no responsibility for care of personal belongings. (ex: clothing, personal effects, etc.)

1. Does not destroy possessions and cares for personal belongings at least in part (e.g., hangs up coat, keeps track of and puts away personal items such as brush or comb).

2. Cares for personal belongings; may need supervision in their general care (e.g., laundry, pressing wrinkled clothing, polishing shoes or may need reminding to seek assistance when possessions fall into disrepair).

3. Cares for personal belongings without supervision and seeks assistance from staff when possessions fall into disrepair.

4. Takes responsibility for total care of personal belongings (ex: maintains clothing, radio and phono; and realizes that repair of belongings is possible from a community resource; may use staff in attaining the repair or purchase of these belongings.)

VD. Prosthetic Device Usage and Maintenance
(ex: hearing aids, glasses, braces, etc.)

0. Client refuses to wear or cannot tolerate prosthetic devices even with supervision.

1. Will wear prosthetic device with or without supervision; may not assume responsibility for function and maintenance.

2. Willingly wears prosthetic device without supervision; may not assume responsibility for function and maintenance.

3. Willingly wears prosthetic device without supervision and is responsible, at least in part, for its functioning. (ex: turning hearing aid "on" and "off," lowering and raising volume, etc.: may not maintain device(s).)

4. Willingly wears prosthetic device without supervision and is responsible for its proper functioning and maintenance with minimal or no supervision.

5. Willingly wears prosthetic device without supervision and is responsible for its proper functioning and maintenance without any supervision.

5.* Client has been assessed and is not known to be hearing impaired, physically handicapped, visually impaired, etc. to a degree that prosthetic devices are required.

VE. Food Purchase

0. Individual has no awareness of supermarkets and grocery stores.

1. Individual has been to supermarket with supervision.

2. Individual has made limited supermarket purchases.

3. Individual has shopped for food when list was provided.

4. Individual has purchased food independently for one week's use.

5. Individual has purchased food from balanced menu he has planned.

VF. Food Preparation

0. Individual is unfamiliar with kitchen utensils and food preparation.

1. Individual has knowledge of foods which do not need cooking.

2. Individual has minimal knowledge of warming previously prepared foods (e.g., t.v. dinners; canned dinners).

3. Individual can prepare simple hot meals (e.g., hamburgers, hot dogs).

4. Individual can plan and prepare simple, balanced meals.

5. Individual can plan and prepare simple, balanced meals using a cookbook or recipe.

6. Individual is competent with food planning and preparation.

VG. Participation in Daily Activities

0. Refuses to participate in daily routine activities.

1. Will participate in at least some daily activities; may need firm prompting to do so.

2. Will participate in all daily activities; may need firm prompting to do so.

3. Willingly participates in activities which he/she desires (ex: cooking, table setting, etc.) without prompting.

4. Actively participates in all daily activities with minimal or no prompting.

5. Accepts responsibility without prompting to perform daily activities necessary for group home functioning. (ex: follows written task schedule for meal preparation, does laundry on assigned evenings, etc.)

VI. Social Skills

VIA. Relation to Authority

0. Individual responds negatively to supervision, and does not initiate interaction with supervisors.

1. Individual is attentive to supervisors but does not initiate interaction when questions arise.

2. Individual is responsive to supervision and will initiate interaction when questions or problems arise.

3. Individual has a positive relationship to supervisors and responds well to supervision.

VIB. Relation to Peers

0. Individual has negative interaction with peers. (fights, arguments).

1. Individual has only limited interaction with peers and does not initiate interaction beyond expressing needs or desire for information.

2. Individual has limited interaction with peers of a social or recreational nature. (Will interact with only a limited number of persons).

3. Individual has consistent interaction with peers of a social or recreational nature. (Is comfortable with a number of persons).

4. Individual has consistent interaction with peers and relates well and appropriately with persons of the opposite sex.

5. Individual has positive relations with most peers and responds appropriately to most social situations.

VI. Social Skills (Score is highest item passed)

A. Relation to authority: _____

B. Relation to peers: _____

SAMPLE PRESENTATION
ACTIVITIES TO IMPROVE SKILLS IN DEFICIT AREAS

List only areas which require improvement	Score	Projected Length of Program in Weeks
	_____	_____
I. Math Skills	_____	_____

IA. Score from ABLE: _____

Activities: _____

_____

_____

IB. Identification and mathematical mechanics of money.

Level: _____

Activities: _____

_____

_____

IC. Functions of money. ____ _____

Activities: _____

_____

_____

ID. Judgments in Utilizing money. ____ _____

Activities: _____

_____

_____

IE. Banking ____ _____

Activities: _____

_____

_____

II. A. General Reading Skills ____ _____

Activities: _____

_____

_____

IIB. Ability to follow instructions. ____ _____

Activities: _____

_____

_____

III. A. Independent Attendance: Leaving for Work ____ _____

Activities: _____

_____

_____

IIIB. Attitudes toward attending work. ____ _____

Activities: _____

_____

_____

IV. A. Community Utilization skills. ____ _____

Activities: _____

IVB. Language in the community. ____ _____

Activities: _____

IVC. Effectiveness of communication in community ____ _____

Activities: _____

V. A. Personal Hygiene. ____ _____

Activities: _____

VB. Room cleaning skills. ____ _____

Activities: _____

VC. Care of personal belongings ____ _____

Activities: _____

VD. Prosthetic device usage and maintenance ____ _____

Activities: _____

VE. Food purchase ____ _____

Activities: _____

VF. Food preparation. ____ _____

Activities: _____

VG. Participation in daily activities. ____ _____

Activities: _____

_____

_____

VI. A. Relation to authority. ____ _____

Activities: _____

_____

_____

VIB. Relation to peers. ____ _____

Activities: _____

_____

_____

SUMMARY OF DEFICIT AREAS

Check all areas for which a program will be planned.

IA. General Math Skills _____

IB. Identification and Mechanics _____

IC. Functions of Money _____

ID. Judgments in Utilizing Money _____

IE. Banking _____

_____

_____

IIA. General Reading Skills _____

IIB. Ability to Follow Instructions _____

IIIA. Independent Attendance: Leaving for Work _____

IIIB. Attitudes Towards Attending Work _____

IVA. Community Utilization Skills _____

IVB. Language in the Community _____

IVC. Effectiveness of Communication in Community _____

VA. Personal Hygiene _____

VB. Room Cleaning Skills _____

VC. Care of Personal Belongings _____

VD. Prosthetic Device Usage and Maintenance _____

VE. Food Purchase _____

VF. Food Preparation _____

VG. Participation in Daily Activities _____

VIA. Relation to Authority _____

VIB. Relation to Peers _____

List areas of focused instruction and goals	Progress Levels 1	2	3	4	5
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					

List areas of minimal instruction and goals	Progress Levels 1	2	3	4	5
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					

1 = Program initiated

2 = Minimal progress made

3 = Progress is satisfactory

4 = Goal achieved

5 = Post test demonstrates continued competence

ABLE

(Adult Basic Learning Examination)

History and Purpose of Test

ABLE is a battery of tests which were designed to measure the level of achievement among adults. ABLE I and II were developed to assess the general educational level of adults who had not completed formal eighth grade education and ABLE III was developed to determine the educational level of adults who had not completed the twelfth grade level. These tests are thus used to determine the high school equivalency of those who did not complete their formal education. ABLE is also used for remedial purposes and is beneficial in helping to evaluate efforts made to raise the educational levels of adults.

The ABLE is given primarily to WORK INCENTIVE (WIN) clients who are interested in Licensed Practical Nurse or Nurse Aide training.

Norm Group

The authors of ABLE feel that ABLE scores should be capable of being translated into a comparison with school children and therefore, grade and high school children (for ABLE II and ABLE III, respectively) were the norm groups used. However, the authors state that local norm group would prove more useful and beneficial for comparison among the students taking the tests in given areas and thus recommend the use of these local norms whenever possible.

Interpretation

The school level achieved for each client taking ABLE III is used for determining his grade level. On the basis of this grade level the raw score is converted into percentile ranks. The raw scores of ABLE II examinees are converted into grade levels.

Betty E. Tarman

APPENDIX IV

A MODEL FOR A GRADUATE LEVEL INTRODUCTORY COURSE ON HEARING IMPAIRMENT AND THE DEVELOPMENT DISABILITIES

MDP Offers Graduate Course
at University of Arizona
by
Carol Cober-Ostby

This semester the University of Arizona Rehabilitation Department is offering a graduate colloquium "Serving Hearing Impaired Developmentally Disabled Persons." The 3 unit class is taught by Dr. Larry Stewart who is assisted by other MDP staff members and various guest lecturers. Students in the class represent the fields of rehabilitation, special education, counseling and guidance, and professionals in the service community. The course is designed to acquaint students with the characteristics, problems, and needs of HIDD children and adults.

Course topics will include the areas of identification and assessment, coordination of services, medical etiologies and treatment, prevention, education and habilitation, hearing aids and other communication techniques, and vocational and employment services. This information will assist the student to develop an understanding of oriorities in serving this population and provide an overview of the state of the art.

COURSE OUTLINE

Rehab. 395D: Colloquium (3 units) Spring, 1979

Serving Hearing Impaired Developmentally
Disabled Persons

Instructor: Larry G. Stewart, Ed. D.

Course Description: This course will acquaint the student with the characteristics, problems, and needs of hearing impaired developmentally disabled children and adults. With new, pioneering knowledge acquired by the Model Demonstration Program, the course should appeal to students from medicine, education,

rehabilitation, speech and hearing, psychology, and other areas of the behavioral sciences.

Objectives:

I. IDENTIFICATION AND ASSESSMENT:

a. Identify behavioral characteristics and prevalence of hearing impaired developmentally disabled (HIDD) persons.

b. Recognize multiple screening techniques, audiologic and psychoeducational diagnostic procedures and the need for interdisciplinary reassessments.

c. Analyze the level of commitment required to provide appropriate recognition, assessment and follow-up services.

II. COORDINATION OF SERVICES:

a. Identify comprehensive service needs of the HIDD population.

b. Develop a flow system for community and state agency services.

c. Design a one-stop general information service to match total needs of HIDD persons with available services.

III. MEDICAL ETIOLOGIES AND TREATMENT:

a. Recognize common disorders which frequently result in developmental disabilities and hearing impairment.

b. Identify medical treatment procedures and sample costs.

c. Illustrate HIDD handicaps which may be reduced or eliminated with early medical intervention.

IV. PREVENTION:

a. Identify direct services which can prevent or reduce potential handicaps.

b. Give examples of indirect preventive strategies.

c. Recognize social issues involved in preventive programs.

V. EDUCATION AND HABILITATION:

a. Know legal basis for providing education services to severely handicapped

children and the role of residential and day school programs in community planning.

b. Relate developmental needs to fundamental instructional techniques and objectives.

c. Outline an individual program plan to provide a continuum of services leading to maximum independence.

VI. HEARING AIDS AND OTHER COMMUNICATION TECHNIQUES:

a. Demonstrate the ability to operate a hearing aid, other communication devices, and alternate communication modes for the severely handicapped.

b. Recognize services needed to facilitate use of special communication approaches.

c. Develop a 24-hour approach to total communication for severely language impaired persons utilizing professional and paraprofessional personnel.

VII. VOCATIONAL AND EMPLOYMENT SERVICES:

a. Know legal basis for employment of severely handicapped persons.

b. Distinguish between prevocational, vocational training, and employment services and the role of state vocational rehabilitation counselors.

c. Recognize the role of housing, recreation, family and counseling in developing work attitudes and daily living skills.

d. Outline a publication to help an employer of an HIMR person.

VIII. PRIORITIES IN SERVING HIDD PERSONS:

a. Know Federal and State policy on developmental disabilities.

b. Recognize roles of parents and advocacy groups in planning, management and evaluation of programs leading to State and Federal legislation.

c. Identify gaps in the research base for a comprehensive, coordinated service delivery system to HIDD persons.

IX. STATE OF THE ART:

a. Learn of current professional literature in the field.

b. Become familiar with current related research studies.

REHAB. 395D
Serving Hearing Impaired Developmentally Disabled Persons

CLASS REQUIREMENTS: Details

I. *Readings* (15% of final grade)

1. Each class member to maintain spiral notebook with a brief, critical summary of each assigned reading. Each summary need not exceed 100 words at the most. "Assigned Readings" are noted for each class.

   Summaries are to be handed in to the instructor following class on May 7. These will be returned at the completion of the final exam on May 14.

II. *Individual Project* (20% of final grade)

1. Each class member is to select an individual project, write it up, and report on it as assigned on either April 16 or April 19. Date of report to be assigned by instructor.

2. Projects should be developed according to these criteria:

   A. Select one topic in the area of research, service, or professional training w/HIDD persons. This topic should represent a "problem," unmet need, or weakness in the current chain of services for HIDD persons.

   B. The topic should be a direct concern of the specific area in which the class member plans to be employed in the near future. I.E., administration, casefinding, assessment, direct educational and rehabilitation services, manpower development, advocacy, materials development, population research, prevention, etc.

   C. The project report should follow this outline:

      a) Statement of Problem
      b) Importance of Problem
      c) Proposed Solution

   D. The proposed project should be outlined in 200 words or less and submitted to the instructor for approval on February 19th.

   E. Keep your project concise, narrow in focus, simple, meaningful, and of brief report. Class presentations will be limited to 20 minutes.

III. *Individual Site Visits* (5% of final grade)

1. Each class member will need to visit two separate programs that serve HIDD persons. Select sites from *State Directory of Services.*

2. A brief but adequate written report on each site visit will need to be turned in to the instructor. Each report should answer these questions:

   A. What is the school/agency/organization doing for *HIDD* persons that recognizes *their* special needs?

   B. Did you *observe* personnel doing these special "things," or did you just *hear* about it?

   C. In 50 words or less, what would *you* do differently for HIDD persons if you were employed by the school/agency/organization?

IV. *Class Attendance* (25% of final grade)

1. This class deals with a "new" population that hasn't been given a lot of attention up to now. Class lectures and discussions will often present information not obtainable elsewhere. Hence, attendance is important, and even more so considering that each meeting equals three regular 50-minute classes. Each missed class will need to be made up via special arrangements with the instructor.

V. *Final Exam* (35% of final grade)

1. The final exam will consist of objective questions (true/false, multiple choice, fill in the blanks).

2. Exam questions will cover class lectures and discussions, readings, guest speaker presentations, and project reports as presented in class.

VI. *Final Course Grade*

1. This course will be graded on the basis of performance in each of the above five areas.

2. The following scores will obtain:

   A. 15 points for satisfactory readings reports.

   B. 20 points for a class project of superior quality.

   C. 5 points for satisfactory reports on two site visits.

D. 25% for perfect class attendance, with two points deducted for each absence that is not made up via special arrangements.

E. 35 points for the final exam, with appropriate deductions according to final exam score.

SAMPLE PRESENTATION

REHAB. 395D
Serving Hearing Impaired Developmentally Disabled Persons

LECTURE: Jan. 29, 1979

IDENTIFICATION AND ASSESSMENT

Overview

I. Overview

II. *Identification: A Professional and Legal Concern*

A. Casefinding, a major professional responsibility

B. Major casefinding agencies

C. Legal Aspects

1) P.L. 94-142
2) P.L. 94-103
3) Rehab. Amendments of 1973, 1978

D. Arizona: State Department of Education; Division of Developmental Disabilities – Mental Retardation (DES); Vocational Rehabilitation

E. Barriers to Identification:

1) Lack of Information
2) Lack of Resources
3) Lack of Coordination

F. Attitudinal Considerations

III. *Definitions*

A. Development Disabilities

1. 1975 Law (94-103)
2. 1978 Law (Rehab. Amendments of 1978)
3. Medical/Psychological vs. Functional
4. Implications for Professionals, Agencies, Schools

1) Assessment: Shift to behavioral data
2) Case Finding
3) Size of Population and Scope of Program
4) Personnel qualifications
5) Funding

B. *Hearing Impairment*

1. Medical/Audiological
2. Functional
3. Lack of Legal Parameters

IV. *Assessment*

A. Assessment by Domain:

1. Autism: Psychiatric/Psychological Domain
2. Cerebral Palsy; Medical Domain
3. Epilepsy: Medical Domain
4. Mental Retardation: Psychological/Education Domain

B. Legal Constraints

1. Assessment by qualified professional
2. Illegal to diagnose w/o proper qualifications, assessment
3. AAMD Criteria

V. *Readings*

1. Stewart, L. *Guide for State D.D. Councils,* Ch. I, II, III, IV, VIII
2. Stewart, L. *National Directory* (all)
3. MDP *HIDD Services in Arizona* (all)
4. P.L. 94-103, definitions
5. Rehab. Amendment of 1978, definitions

SAMPLE PRESENTATION

Rehab. 395D
LECTURE: Feb. 19, 1979
L. Stewart

PREVENTION

1. Prevention of the handicaps of "hearing impairment and developmental disabilities" may be classified in two areas: prevention from occurrence and prevention from increasing severity.

2. Hearing impairment as well as the developmental disabilities occur as a result of "assault" or genetics.

   a. Within the body – genetic, inherited. Defective chemistry, structure of body cells – chromosomal and metabolic anomalies that alter brain structure or function

   b. Outside the body – assault and environmental influences. Examples are infection, trauma, poor nutrition, poisoning, interference with blood supply

   c. Sometimes, both within and outside the body influences act together

3. The nature and severity of the handicaps of a developmental disability and hearing loss are determined in large part by the nature of the etiologic agent and its impact on the brain, the stage of development the brain is in at onset, and the site of the damage or dysfunction.

4. Prenatal insults occur prior to the birth of the infant. Rubella, for example, if it occurs within the first three months of prenatal development interferes with the actual structural development of the brain and other systems. Later onset (after three months) also affects the embryo, but the damage is less extensive or dramatic since the organs have developed.

5. Perinatal insults (during labor, delivery) most often involve head trauma, interference with oxygen reaching the brain, and, in some cases, toxic effects of medication.

6. Postnatal insults occur after the infant is born. Examples include head trauma, malnutrition, meningitis.

7. The stage of neurological development of the brain determines the degree of susceptibility to damage as well as the ability of the brain to recover.

8. There are, then, a variety of insults that can occur at a variety of stages of development at a variety of brain sites. Hence, there is a wide range of disabilities that may occur and a correspondingly wide range of handicaps.

There is, for instance, the child of normal IQ who is clumsy and is learning disabled, and the child who is spastic and of profound mental deficiency. In between are many types of impairments.

9. Prevention is founded upon a solid understanding of causative factors. Once causes are understood, prevention may be carefully planned.

10. Many, many developmental disabilities and hearing impairments may be prevented from occurring through proper nutritional care of the mother during pregnancy as well as proper care of the child after birth. Others may be prevented via genetic counseling and by proper medical care before and after birth (Rh Factor incompatibility, for instance, can be controlled). Still others may be prevented via proper medical care during infectious illnesses, safety practices in the home, and other related measures.

11. Prevention of severity of effects of disabilities may be accomplished via such measures as early identification and treatment as well as ongoing appropriate education and rehabilitation measures.

12. There are a variety of Early Infant Screening methodologies. A review of the literature will provide indepth information in this area. The CRIBOGRAM system used to detect early hearing loss is but one example.

13. Early screening is predicated on the right of the child to proper care and early identification of disabilities and impairments.

14. At the same time, care must be taken in early labeling of a child. The purpose of labeling is for diagnosis *and* treatment. The "Rumplestiltskin Complex" – or labeling for labeling's sake, as Rumplestiltskin did when he figured if he could come up with the queen's name all problems would be solved – is harmful and may affect a child throughout life.

15. The goal of diagnosis is to identify developmental problems of the child: intellectual, motor, language, social status, health, and nutritional.

16. If we can identify developmental problems early, we can intervene early. The longer a disability is overlooked, the more pervasive will be the results. Learning disabilities, once identified generally in the third and fourth grade, can now be identified during preschool years and earlier. The growth of infant and preschool child care programs should add to the effectiveness of early diagnosis.

17. The importance of proper maternal care cannot be emphasized enough. Prematurity, a leading cause of infant disabilities, can be disastrous when the

birthweight is 5½ pounds or less or the term of pregnancy is 37 weeks or less. Prematurity results in such problems as oxygen deficiency to the brain, unpreparedness of the infant to withstand the normal assaults of the outside world, hyperbilirubinemia, and other problems. Rh Factor Incompatibility also is a major causative agent in disabilities of the brain.

APPENDIX V

A MODEL FOR COMMUNITY-BASED RESIDENTIAL PROGRAMMING FOR HIDD PERSONS

by

Joseph B. Perine

A primary resource needed for *all* severely handicapped persons at this time is community-based residential programming. The influence of home and community can be the greatest positive factor in the life of any handicapped person, especially an individual who is hearing impaired and developmentally disabled. The HIDD person needs positive role models in the areas of daily living skills and communication, and these models are not available on a consistent basis in a large residential (institutional) facility. Institutions tend to emphasize "training" often to the exclusion of living. Each person learns a major percentage of his or her social and adaptive behavior through interaction and communication within a relaxed, natural environment. This setting is not found within a typical institutional program.

Prerequisite to the development of community-based residential programs which integrate the HIDD person into another population base, is an intermediate step that must be taken immediately following "deinstitutionalization." For lack of a more appropriate term, this step or alternative may be called a "transitional living facility." The need for a residential component of this type is set forth in the following excerpt from Position Paper No. 2 of the Arizona Advisory Committee for Deaf-Blind Persons (AACDBP):

> While the "end" of the continuum must be the full physical and social integration of the client into the community, the *"beginning" of the continuum should be specialized residential,* educational and vocational services in settings *explicitly designed to meet the unique needs of the client with a sensory impairment and to encourage the client's maximum independent functioning within that setting.* Of course, any client should be able to enter the service continuum at whatever point is best suited to meet the client's specific needs.
>
> *The sole purpose of the specialized, separate programs in residential, educational and vocational services should be to assist the client to move to increasingly less intense and less specialized programs. Specialization should never be permitted to become segregation.*

This point of view has been reinforced through direct federal legislation in Title VII of the 1978 amendments to the Rehabilitation Act of 1973. The explanation of the "Comprehensive Services for Independent Living" portion of this amendment, Sec. 701-711 are as follows:

"TITLE VII – COMPREHENSIVE SERVICES FOR INDEPENDENT LIVING

"Part A – Comprehensive Services

"PURPOSE

"Sec. 701. The purpose of this title is to authorize grants (supplementary to grants for vocational rehabilitation services under title I) to assist States in providing comprehensive services for independent living designed to meet the current and future needs of individuals whose disabilities are so severe that they do not presently have the potential for employment but may benefit from vocational rehabilitation services which will enable them to live and function independently.

"ELIGIBILITY

"Sec. 702. (a) Services may be provided under this title to any individual whose ability to engage or continue in employment, or whose ability to function independently in his family or community, is so limited by the severity of his disability that vocational or comprehensive rehabilitation services of appreciably greater duration than those vocational or comprehensive rehabilitation services required for the rehabilitation of a handicapped individual are required to improve significantly either his ability to engage in employment or his ability to function independently in his family or community. Priority of services under this part shall be given to individuals not served by other provisions of this Act.

"(b) For purposes of this title, the term 'comprehensive services for independent living' means any appropriate vocational rehabilitation service (as defined under title I of this Act) and any other service that will enhance the ability of a handicapped individual to live independently and function within his family and community and, if appropriate, secure and maintain appropriate employment. Such services may include any of the following: counseling services, including psychological, psycho-therapeutic, and related services; housing incidental to the purpose of this section (including appropriate accommodations to and modifications of any space to serve handicapped individuals); appropriate job placement services; transportation; attendant care; physical rehabilitation; therapeutic

treatment; needed prostheses and other appliances and devices; health maintenance; recreational activities; services for children of pre-school age, including physical therapy, development of language and communication skills, and child development services; and appropriate preventive services to decrease the needs of individuals assisted under the program for similar services in the future.

"ALLOTMENTS

"Sec. 703. (a) (1) From sums made available for each fiscal year for the purposes of allotments under this subpart, each State whose comprehensive services plan has been approved under section 705 shall be entitled to an allotment of an amount bearing the same ratio to such sums as the population of the State bears to the population of all States. Except as provided in paragraph (2), the allotment to any State under the preceding sentence shall be not less than $200,000 or one-third of 1 percent of the sums made available for the fiscal year for which the allotment is made, whichever is greater, and the allotment of any State under this section for any fiscal year which is less than $200,000 or one-third of 1 percent of such sums shall be increased to the greater of the two amounts.

"(2) For purposes of this subsection, Guam, American Samoa, the Virgin Islands, the Northern Mariana Islands, and the Trust Territory of the Pacific Islands shall not be considered as States and shall each be allotted not less than one-eighth of 1 percent of the amounts made available for purposes of this subpart for the fiscal year for which the allotment is made.

"(b) Amounts necessary to increase the allotments of States under paragraph (1) or to provide allotments under paragraph (2) shall be derived by proportionately reducing the allotments of the remaining States under paragraph (1), but with such adjustments as may be necessary to prevent the allotment of any such remaining States from being thereby reduced to less than the greater of $200,000 or one-third of 1 percent of the sums made available for purposes of this subpart for the fiscal year for which the allotment is made.

"(c) Whenever the Commissioner determines that any amount of an allotment to a State for any fiscal year will not be utilized by such State in carrying out the purposes of this title, he shall make such amount available for carrying out the purposes of this section to one or more of the States which he determines will be able to use additional amounts during such year for carrying out such purposes. Any amount made available to a State for any fiscal year pursuant to the preceding sentence shall, for the purposes of this section, be regarded as an

increase in the State's allotment (as determined under the preceding provisions of this section) for such year.

"PAYMENTS TO STATES FROM ALLOTMENTS

"Sec. 704. (a) From each State's allotment for a fiscal year under section 703, the State shall be paid the Federal share of the expenditures incurred during such year under its State plan approved under section 705. Such payments may be made (after necessary adjustments on account of previously made overpayments or underpayments) in advance or by way of reimbursement, and in such installments and on such conditions as the Commissioner may determine.

"(b) (1) The Federal share with respect to any State for any fiscal year shall be 90 percent of the expenditures incurred by the State during such year under its State plan approved under section 705.

"(2) The non-Federal share of the cost of any project assisted by an allotment under this subpart may be provided in kind.

"(3) For the purposes of determining the Federal share with respect to any State, expenditures by a political subdivision of such State shall, subject to regulations prescribed by the Commissioner, be regarded as expenditures by such State.

"STATE PLANS

"Sec. 705. (a) In order to be eligible for grants under this part, a State shall submit to the Commissioner a State plan for a three-year period for providing comprehensive services for independent living to severely handicapped individuals, and upon request of the Commissioner, shall make such annual revisions in the plan as may be necessary. Each such plan shall–

"(1) designate the designated State unit of such State as the agency to administer the programs funded under this part;

"(2) demonstrate that the State has studied and considered a wide variety of methods for providing comprehensive services to severely handicapped individuals (such as regional and community centers, halfway houses, and patient-release programs) and that the State will provide, to the maximum extent feasible, meaningful alternatives to institutionalization;

"(3) (A) describe the quality, scope, and extent of the comprehensive services for independent living to be provided to

handicapped individuals under this part, and specify the State's goals and plans with respect to the distribution of funds received under part B of this title; and

"(B) provide satisfactory assurances that facilities used in connection with the delivery of services assisted under this part and part B of this title will comply with the Act of August 12, 1968, commonly known as the Architectural Barriers Act of 1968;

"(4) provide assurances that (A) an individualized written rehabilitation program meeting the requirements of section 102 will be developed for each handicapped individual eligible for independent living services under this part; (B) such services will be provided in accordance with such program; and (C) that such program be coordinated with the individualized written rehabilitation program, habilitation plan, or eduction program for such individual required under section 102 of this Act, section 112 of the Developmental Disabilities Services and Facilities Construction Act, and sections 612(4) and 614(a)(5) of the Education for All Handicapped Children Act of 1975, respectively;

"(5) provide assurances that the State will conduct periodic reviews of the progress of individuals assisted under this title to determine whether services provided to such individuals should be continued, modified, or discontinued;

"(6) provide assurances that special efforts will be undertaken to provide technical assistance to urban and rural poverty areas with respect to the provision of comprehensive services for severely handicapped individuals and describe such efforts;

"(7) provide assurances that handicapped individuals shall have a substantial role in developing the State plan;

"(8) provide assurances that not less than 20 percent of the funds received by a State under this part shall be used to make grants to local public agencies and provide nonprofit organizations for the conduct of independent living services except that the Commissioner may waive the requirement of this clause if the Commissioner determines, on the basis of evidence submitted by the State, that such State cannot feasibly use the funds required to be expended under this section for the purposes of this clause; and

"(9) contain such other information, and be submitted in such form and in accordance with such procedures, as the Commissioner may require.

"(b) As soon as practicable after receiving a State plan submitted under subsection (a), the Commissioner shall approve or disapprove such plan. The Commissioner shall approve any State plan which he determines meets the requirements and purposes of this section. The provisions of subsections (b), (c), and (d) of section 101 of this Act shall apply to any State plan submitted to the Commissioner pursuant to this section, except that for purposes of this section, all references in such subsections to the Secretary shall be deemed to be references to the Commissioner.

"Part B – Centers for Independent Living

"Grant Program Established

"Sec. 711. (a) The Commissioner may make grants to any designated State unit which administers the State plan under section 705 to provide for the establishment and operation of independent living centers, which shall be facilities offering the services described in subsection (c) (2).

"(b) No grant may be made under this section unless an application therefor has been submitted to and approved by the Commissioner. The Commissioner may not approve an application for a grant unless the application –

"(1) contains assurances that the designated State unit will use funds provided by such grant in accordance with subsection (c); and "(2) contains such other information, and is submitted in such form and in accordance with such procedures, as the Commissioner may require.

"(c) An application by a public or nonprofit agency or organization for such grant shall –

"(1) provide assurances that handicapped individuals will be substantially involved in policy direction and management of such center, and will be employed by such center;

"(2) contain assurances that the independent living center to be assisted by such grant shall offer handicapped individuals a combination of independent living services, including, as appropriate –

"(A) intake counseling to determine the client's need for specific rehabilitation services;

"(B) referral and counseling services with respect to attendant care;

"(C) counseling and advocacy services with respect to legal and economic rights and benefits;

"(D) independent living skills, counseling, and training, including such programs as training in the maintenance of necessary equipment and in job-seeking skills, counseling on therapy needs and programs, and special programs for the blind and deaf;

"(E) housing and transportation referral and assistance;

"(F) surveys, directories, and other activities to identify appropriate housing and accessible transportation, and other support services;

"(G) health maintenance programs;

"(H) peer counseling;

"(I) community group living arrangements;

"(J) education and training necessary for living in the community and participating in community activities;

"(K) individual and group social and recreational activities;

"(L) other programs designed to provide resources, training, counseling, services, or other assistance of substantial benefit in promoting the independence, productivity, and quality of life of handicapped individuals;

"(M) attendant care and training of personnel to provide such care; and

"(N) such other services as may be necessary and not inconsistent with the provisions of this title; and

"(3) contain such other information, and be submitted in such form and in accordance with such procedures, as the Commissioner may require.

"(d) If, within six months after the date in each fiscal year on which the Commissioner begins to accept applications from designated State units under this section, a designated State unit in a State has not submitted such an application, the Commissioner may accept applications for grants under this section from local public agencies or private nonprofit organizations within such State. After the receipt of such applications, the Commissioner may make grants to such agencies or organizations for the purpose of establishing independent living centers to provide the services described in subsection (c)(2).

Given the legislative mandate and apparent public sentiment for the creation of community-based residential alternatives, it is appropriate that a model for a Transitional Living Facility to be implemented on a long-term basis. Whereas the goals of such a facility are outlined in the AACDBP position paper and in the amendment to the Rehabilitation Act of 1973, there needs to be an operational format established which will facilitate these goals.

Initially, a facility developer must consider the *site* for the program since this factor can be a major contributing force behind the success of the effort. Several practical criteria must be kept in mind during the site investigation stages. These are:

1. Interaction with nonhandicapped persons
2. Access to public transportation
3. Access to medical and health-related facilities
4. Proximity to entertainment/recreation area (movie theaters, parks, etc.)
5. Access to a variety of vocational experiences
6. Proximity to shopping areas

In addition, the developer must be cognizant of and adhere to all zoning regulations. This is a relatively simple process which involves close communication with the local zoning board and/or civic leadership.

In fact, several states have initiated legislation to provide opportunities for residential options within the community. New York, for example, has three acts which are designed specificially to facilitate the development of residential

accommodations. Assembly Bill 12501-A creates a registry of *all* licensed residential facilities so that there can be consistent, coordinated planning for future development of residencies for clients of Mental Health/Mental Retardation/Developmental Disabilities. Assembly Bill 12465-A requires all local government units to provide for the development of appropriate residential accommodations consistent with the current and anticipated needs of mentally disabled residents. The provisions must be included in annual plans which are submitted in order to obtain state aid for mental hygiene services. Finally, Senate Bill 8212-B mandates local government involvement in the determination of residential sites. This bill prohibits the establishment of any new residential facility without substantial input from the municipality including the option to suggest suitable sites.

Once the site has been located, the developer must decide upon the organization and operation of the transitional facility.

THE TRANSITIONAL FACILITY

A transitional living facility can serve as an *adjunct* to current programs to improve the service potential and concomitant community opportunities for persons who are hearing impaired and developmentally disabled. The generic functions of a facility of this type would be as follows:

- Diagnostic Evaluation– 24-hour diagnosis can be carried out to include skill assessments in the area of communication as well as activities of daily living.
- Prescriptive Programming– effective programs can be developed, implemented, modified, and finalized in an environment designed specifically to meet the unique needs of the HIDD population.
- Support Services– a support network can be developed within the facility so that 1) a trained staff person can be assigned to each residential placement with a client, and 2) trainers are available on a needs basis to serve the needs of the client and/or the community worker.

Each of these program services will be interrelated with the others to provide training in the areas of total communication and activities of daily living. Once the HIDD client has acquired skill in these areas, he or she will be ready for community placement on a declining dependence basis.

Staffing for a facility of this type is an area requiring special attention, for the personal interaction between staff and client can have a significant effect upon the

ultimate success of the individual. Therefore, we must look carefully at the following functions, and types of staff best suited to carry out the associated duties.

Program Services– the functions included in this category include audiological, physical, psychoeducational, and social/emotional programming and diagnosis. In order to insure the thoroughness and appropriateness of these functions, one should maintain a diagnostic staff of at least these positions:

1) An *audiologist*(s) trained in total communication and with skill in pure tone and impedance audiometry as well as facility with play audiometry and sound field testing. There should also be access to evoked response audiometry where such a service is required.

2) A *psychoeducational specialist*(s) who has demonstrated expertise in total communication and who has knowledge of psychometric techniques for use with a sensory impaired/multiply handicapped population.

3) A *counselor*(s) who has skill in total communication and who is familiar with observational and pencil/paper assessments of persons who are hearing impaired and developmentally disabled.

4) A *physical/occupational therapist*(s) with the necessary skills in total communication and physical skill assessment to perform accurate diagnoses of clients' potential abilities in the areas of daily living activities and sign language.

5) A *vocational evaluator* with skill in total communication and who has demonstrated expertise in the evaluation of vocational and prevocational skills with persons who are hearing impaired and developmentally disabled.

6) *Instructors* who are able to develop meaningful educational/habilitative/rehabilitative programs following consultation with diagnostic personnel. The instructional staff must have skills in the areas of total communication, behavioral objective

development, program design, formative and summative evaluation procedures, and behavior management techniques.

7) *Ancillary Staff Consultants* available on a will-call basis. This cadre of professionals should include neurologists, psychiatrists, otologists, ophthalmologists, family practioners, media specialists. Other special needs should be accommodated by specific contractual arrangements.

8) A *community liaison*(s) who has facility in total communication and who coordinates diagnostic and programming efforts with available community resources and demonstrated community needs.

•Residential Services– the primary function of staff in this area is to insure the safety and well being of clients during the normal sleeping hours. In addition, these staff persons should be able to use total communication in informal teaching situations according to the instant needs of the client.

•Administrative Services– the functions of this area require at least three types of positions: *Director, Assistant Director, Clerk/Typist.* Whereas the responsibilities of these positions are interrelated, the tasks unique to each are as follows:

Director – Must have facility in total communication, and is responsible for acquisition of funds, budget development and maintenance, policy making, coordination with other agencies, overall program supervision.

Assistant Director – Must have facility in total communication, and is responsible for staff supervision, program coordination, public information, other as assigned by Director.

Clerk/Typist – Must have facility in total communication and is responsible for all clerical tasks including typing, maintenance of supplies, bookkeeping, and other as assigned by the Director and/or Assistant Director.